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The Impact of a Sensory Garden Intervention for Individuals with Dementia

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THE IMPACT OF A SENSORY GARDEN INTERVENTION
FOR INDIVIDUALS WITH DEMENTIA

A Thesis
Presented to
the Graduate School of
Clemson University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science
Recreational Therapy

by
Haley Elizabeth Collins
August 2019

Accepted by:
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ABSTRACT

The purpose of this study was to determine the impact of sensory gardens on agitation and quality of life for people with dementia. The sensory garden consisted of plants that stimulated all the senses. Four people diagnosed with dementia residing in assisted living participated in the multiple treatment single-subject design (A_1 -B-BC- A_2) study. Baseline phase A_1 lasted two-weeks, intervention B and BC were four-weeks each, and return to baseline A_2 was two-weeks, for a total of 12 weeks. Intervention B was an indoor sensory garden and intervention BC was an approximated outside sensory garden. Data revealed positive trends following the sensory garden interventions on decreasing agitation and improving quality of life. Intervention B worked best for two participants and intervention BC for the remaining two participants. Applications to recreational therapy practice are provided.

DEDICATION

I dedicate this thesis to my parents Mandy and Rob Collins. They continually encouraged me to keep going and to not forget to have some fun along the way. I would also like to dedicate this to my Grandpa Fred Collins, who inspired me to seek out better ways to care for those with dementia.

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CHAPTER 1

Introduction

Dementia is a neurocognitive disorder that's primary feature is progressive cognitive decline (Tortosa-Martinez & Yoder, 2015). The effects of dementia on a person are drastic. Dementia results in people slowly losing their memory, communication skills, and judgement to a degree that affects their activities of daily living, causes stress, and may potentially reduce their quality of life (Buettner, Lundedren, Lago, Farrell, & Smith, 1996). People with dementia also experience a decrease in meaningful activity participation due to cognitive and physical decline (Buettner & Kolanowski, 2003). Dementia typically affects people later in life but may start as early as 65 years old (Tortosa-Martinez & Yoder, 2015). There are an increasing number of people living over the age of 65 years, and with the increase in age there is expected to be an increase from the current population of people living with dementia, approximately 35.6 million people in the world, doubling every 20 years (Prince, Bryce, Albanese, Wimo, Ribeiro, & Ferri, 2013). There is currently no cure for dementia, and further, pharmacological treatments often have harsh negative side-effects (Buckley & Salpeter, 2015). With an increase in the number of people with dementia, it is important to gain a better understanding of their experience and how healthcare providers may help improve their quality of life through non-pharmacological treatments.

Recreational therapy has the unique opportunity of being a nonpharmacological treatment to help people with dementia improve their quality of life (Buettner & Ferrario, 1998; Buettner, et al., 1996; Buettner & Kolanowski, 2003; Kaufman, 2016).

Recreational therapy is a holistic healthcare profession, addressing the physical, emotional, cognitive, social, and spiritual needs of an individual. Recreational therapists focus on systematically providing activity-based interventions to obtain goals for a client (Austin, 2015a). Recreational therapy has been shown to help improve overall functioning and cognition, and decrease agitation and depression in comparison to traditional nursing home activities for people with dementia (Buettner, et al., 1996; Buettner & Ferrario, 1998; Buettner, Fitzsimmons, & Atav, 2006). One type of intervention recreational therapists utilize is horticulture activities to aid in reducing stress and decreasing ill-being (Gigliotti, Jarrott, & Yorgason, 2004). Horticulture activities are any intervention that utilizes plants and they have been shown to improve quality of life, increase engagement, and decrease disruptive behaviors for people with dementia (Barnicle & Midden, 2003; Gigliotti & Jarrott, 2005; Gigliotti, et al., 2004; Jarrott, Kwack, & Relf, 2002). In addition, research has shown that for people with dementia, being outside leads to a quicker reduction in the body's stress response than being inside, as well as an increase in concentration (Ottosson & Grahn, 2005). A study about traditional nursing home activities (singing, jokes, and crafts) conducted outdoors for people with dementia versus inside activities, was shown to contribute to improved sleep and a decrease in verbal disruptive behaviors (Connell, Sanford, & Lewis, 2007). This study confirmed previous research that recreation activities conducted outside helped to reduce the body's stress response (Ottosson & Grahn, 2005). Since both recreational therapy and being outdoors have been shown to benefit people with dementia, it stands to reason that recreational therapy utilizing a sensory garden for

people with dementia would result in significant benefits. However, there is a gap in knowledge about sensory garden use in recreational therapy practice that requires further study to better serve those who have dementia.

There is a theoretical basis that supports the idea of recreational therapy utilizing a sensory garden. First, the Theory of Personhood states that a person with dementia struggles to maintain their intersubjectivity (i.e., ability to understand yourself based on how you relate to people and they relate to you), therefore losing their personhood (Kitwood, 1992). This theory further states that to reclaim their intersubjectivity, a person with dementia needs to fulfill the psychological needs of comfort, attachment, inclusion, occupation, and agency as determined by The Model of Psychological Needs & Well-Being in Dementia developed from The Theory of Personhood (Kitwood, 1992; Kitwood, 1997; Kaufman, 2016). The next theory supporting this study's intervention is the Theory of Supportive Gardens, which states that the four main functions of a garden in a healthcare setting are to provide stress relief and restoration through a sense of control, social support, physical movement and exercise, and access to nature and other positive distractions (Ulrich, 1999). These theories work together to support the concept of recreational therapy utilizing a sensory garden as a garden is an essential environment to experience comfort, attachment to leisure interests, inclusion into social interactions and activities, a sense of agency from being able to make the choice to seek a temporary escape from the healthcare setting and the stress associated with it. When a person with dementia experiences comfort, attachment, inclusion, agency, they will experience a higher level of intersubjectivity and therefore improved quality of life.

The reason for this study was to merge the two ideas that 1) recreational therapy is good for people with dementia and 2) that engaging with nature is beneficial for people with dementia. The purpose of this study was to determine the impact of sensory gardens on agitation and quality of life for people with dementia.

CHAPTER 2

Literature Review

Dementia is a large, encompassing diagnosis of a variety of neurocognitive diseases that cause a person to regress in functioning in almost all aspects of life over the diseases' progression (Nolen-Hoeksema & Marroquin, 2017; Prince, et al., 2013).

Recreational therapy is a holistic profession that may aid people with this diagnosis to maintain and even improve functioning. However, the effectiveness of recreational therapy, specifically utilizing a sensory garden, to maintain and improve functioning of people with dementia needs to be explored to get a better understanding of how to help clients improve their quality of life with empirical evidence and theoretical backing.

Dementia

Definition and statistics. Dementia is a neurocognitive disorder of progressive decline in cognitive functioning (Grand, Caspar, & MacDonald, 2011; Prince, et al., 2013; Tortosa-Martinez & Yoder, 2015). There are various causes of dementia with the most common being categorized into Alzheimer's, vascular, Lewy body, and frontotemporal dementia (Fiest, et al., 2016; Tortosa-Martinez & Yoder, 2015). As of 2010, approximately 35.6 million people worldwide lived with dementia and that number is to double every 20 years (Prince, et al., 2013). The increase in people diagnosed with dementia is likely due to the increase of people above the age of 65, as the greatest risk factor for dementia is age (Fiest, et al., 2016). After the age of 65, the prevalence of dementia doubles every five years (Fiest, et al., 2016). In a study of 438 incident cases of dementia over a span of four years, the average age of onset was 84 for women and 83

for men, with 71% of the cases being women (Xie, Brayne & Matthews, 2008). After the onset of dementia, a woman may expect to live 4.6 years and a man for 4.1 years (Xie, et al., 2008).

Symptoms. The decline in patient's cognitive functioning with dementia results in difficulty with memory, executive functioning, attention, and independence (Buettner & Ferrario, 1998; Gigliotti, et al., 2004; Kitwood, 1997; Tortosa-Martinez & Yoder, 2015). This decline hinders their ability to participate in work, community life, and socializing (Buettner, et al., 1996). The experience of going through dementia is difficult on the individual. It attacks who they are as a person as they struggle to maintain their identity while losing their memory (Holst & Hallberg, 2003; Ostwald, Duggleby, & Hepburn, 2002; Steeman, Casterlé, Dierckx, Godderis, & Grypdonck, 2006). It is important to note that each person's experience is different, yet there are some common themes that arise in their experiences (Holst & Hallberg, 2003; Kitwood, 1997; Ostwald, et al., 2002; Steeman, et al., 2006). At the first signs that something is different, the person may struggle with feeling out of control of their life (Steeman, et al., 2006). The awareness of having dementia also results in uncertainties for the person. They may fear not being able to maintain their personal identity, or the uncertainty of how the effects of the disease will impact them and those they love (Ostwald, et al., 2002; Steeman, et al., 2006). Once the disease progresses, they experience the loss of control that they were initially worried about (Holst & Hallberg, 2003; Ostwald, et al., 2002; Steeman, et al., 2006). Other people begin to take control of their lives for them, treating them as an object rather than a person, causing a decrease in self-esteem for the person with

dementia (Holst & Hallberg, 2003). Along with a lack of control, the memory loss they experience is accompanied with feelings of irritation, frustration, fear, shame, guilt, uselessness, and worthlessness (Ostwald, et al., 2002; Steeman, et al., 2006). Because of these feelings, people with dementia engage in self-protective and adaptive strategies that are either negative or positive; such as denial of problems and self-isolation or talking about their memory impairment and trying to stay engaged in activities (Ostwald, et al., 2002; Steeman, et al., 2006). In the later stages of dementia, people experience agitation and disruptive behaviors (Kales, Gitlin, & Lyketsos, 2015). These behaviors often disrupt activity groups, performance of activities of daily living, and other life events in ways that threaten the themselves or others around them (Barton, Ketelle, Merrilees & Miller, 2016; Buettner, et al., 1996; Dyer, Harrison, Laver, Whitehead & Crotty, 2018; Kales, et al., 2015). This type of behavior results in their removal from activities, isolation, and additional hospitalizations (Buettner, et al., 1996; Kales, et al., 2015), which then hinders the person psychologically. Therefore, it is important that people with dementia are treated properly, given respect, a sense of belonging, and are included in activities they find meaningful in order to help them manage their symptoms (Burgener & Dickerson-Putman, 1999; Moyle, Venturto, Griffiths, Grimbeek, McAllister, Oxlade, & Murfield, 2011; Steeman, et al., 2006).

Treatments. There is currently no cure for dementia (Buckley & Salpeter, 2015; Grand, et al., 2011). However, there are pharmacological treatments available for people experiencing symptoms that are severe or dangerous, but pharmacological treatments are not recommended for most cases (Reus, et al., 2016). The most common and

recommended treatments for dementia are nonpharmacological (Grand, et al., 2011; Kales, et al., 2015; Reus, et al., 2016; Salzman, et al., 2008).

Pharmacological treatments. Two primary pharmacological treatments offered to help reduce behavioral symptoms and improve cognition specifically for dementia are cholinesterase inhibitors (ChEIs) (Donepezil, Galantamine, and Rivastigmine), and the low-affinity N-methyl-D-aspartate (NMDA) antagonist Memantine (Buckley & Salpeter, 2015; Kuronen, Koponen, Nykänen, Karppi, & Hartikainen, 2015). Additionally, atypical antipsychotics are a type of pharmacological treatment that are not explicitly meant to treat dementia but are used to treat severe agitation and aggression symptoms of dementia (Salzman, et al., 2008). These treatments attempt to reduce agitation and improve cognition for people with dementia (Kuronen, et al., 2015).

In a systematic review of 257 studies on the effects of ChEIs by Buckley and Salpeter (2015), ChEIs resulted in small cognitive, functional, and behavioral gains, but gains were not clinically significant, and the gains decreased after 1-2 years of use (Buckley & Salpeter, 2015). Clinical significance is when the effects of an intervention results in change to the target behavior that is determined meaningful to the individual by the researcher based on their extensive knowledge of behavior and interpretation of the data (Buckley & Salpeter, 2015; Schulz, et al., 2002). Not only did the cognitive, functional, and behavioral gains from ChEIs decrease over time, but ChEIs have many negative side effects (Buckley & Salpeter, 2015). People taking ChEIs experienced gastrointestinal issues (abdominal pain, anorexia, diarrhea, nausea, vomiting), neurological difficulties (abnormal dreams, dizziness, headache, insomnia, tremor,

vertigo), cardiovascular issues (syncope, edema), and in general experienced asthenia, fatigue, muscle cramps, weight loss, and at least one adverse event (Buckley & Salpeter, 2015). The two most serious side effects of ChEIs were weight loss and syncope; these side effects alone are enough to greatly reduce the quality of life of a person with dementia to the extent the drug should not be used (Buckley & Salpeter, 2015; Kuronen, et al., 2015).

The drug Memantine was also studied in the systematic review of 257 randomized trials by Buckley and Salpeter (2015) and Memantine produced minimal benefits in cognition and function. The cognitive and functional benefits derived from taking Memantine had no clinical significance and the cognitive benefits often dissipated after a few months (Buckley & Salpeter, 2015; Qaseem, et al., 2008). Memantine is less effective than ChEIs, but is used because it has fewer side effects that greatly impacted quality of life (Buckley & Salpeter, 2015).

Atypical antipsychotic drugs are another medication used to treat the serious dementia-related aggression and agitation, yet it is not FDA approved for this use. Atypical antipsychotics increase the risk of people with dementia experiencing a stroke, so it is only suggested to use when nonpharmacological interventions fail to decrease severe disturbing behaviors (Salzman, et al., 2008). Due to the minimal benefits provided by these drugs and the number of side-effects, it is important to explore non-pharmacological treatments to help improve the quality of life of people with dementia by reducing agitation.

Non-pharmacological treatments. While pharmacological treatments are suggested for people with experiencing severe agitation with dementia, the American Psychological Association (2016) recommends that nonpharmacological approaches should be used prior to non-emergency use of pharmacological treatments or in conjuncture with pharmacological treatments. There are a variety of nonpharmacological treatments that may be used to treat agitation for people with dementia. Some of the most commonly used in dementia care are environmental adaptations, caregiver training, and psychosocial interventions (Barton, et al., 2016; Buettner, et al., 2006; Dyer, et al., 2018; Grand, et al., 2011; McDermott, et al., 2018; Moniz Cook, De Vugt, Verhey & James, 2012; Salzman, et al., 2008).

Deficits in information processing due to dementia causes people to have difficulties understanding their environment (Barton, et al., 2016). Environmental adaptations are beneficial in reducing the confusion, irritability, and the frustration of not being able to comprehend their surroundings (Barton, et al., 2016). Adaptations may be as simple as reducing clutter, noise, and removing problematic items like locked doors and credit cards (Barton, et al., 2016; Rappe & Topo, 2007). In a study of 35 care facilities, 275 residents with dementia and/or memory loss were assessed for quality of life based on the quality of their environment (Fleming, Goodenough, Low, Chenoweth & Brodaty, 2016). It was found that when residents had the opportunity to take a walk outside, to be in a familiar environment, to have opportunities for privacy and social interaction, and the possibility to engage in activities of daily living, they self-reported experiencing higher subjective well-being (Fleming, et al., 2016). Environmental

adaptations are one simple way to improve the lives of people with dementia and may be combined with other nonpharmacological treatments (Barton, et al., 2016; Fleming, et al., 2016; Rappe & Topo, 2007).

Caregiver training is another nonpharmacological intervention that may help to reduce agitation for people with dementia (Barton, et al., 2016; Grand, et al., 2011; Salzman, et al., 2008). When caregivers are educated on dementia and how to manage disturbing behaviors there is a decrease of those behaviors (Grand, et al., 2011). Such programs that aim to aid caregivers are Savvy Caregiver, STAR-C, and REACH (Barton, et al., 2016; Salzman, et al., 2008). These programs work on teaching effective communication, how to match activities, the environment to the abilities of the person with dementia, and how to manage behaviors in a way that reduce the impact of disturbing behaviors on the caregiver and for the person with dementia (Barton, et al., 2016; Salzman, et al., 2008).

Psychosocial interventions are a nonpharmacological treatment that can be any intervention involving physical, cognitive, or social activities to improve quality of life, self-esteem, increase social and communication skills, and to decrease disturbing behaviors in people with dementia (Grand, et al., 2011; McDermott, et al., 2018). Common psychosocial interventions are those involving physical activities, cognitive stimulation, and behavioral management (Grand, et al., 2011; McDermott, et al., 2018; Vernooij-Dassen, Vasse, Zuidema, Cohen-Mansfield & Moyle, 2010). In a synthesis of 22 intervention reviews, physical exercise was found to improve physical function, cognitive function, and activities of daily living skills with multi-component exercise

being the most beneficial (McDermott, et al., 2018). Cognitive stimulation was shown to improve cognitive functioning, increase quality of life, and decrease disturbing behaviors for people with dementia (Grand, et al., 2011; McDermott, et al., 2018; Vernooij-Dassen, et al., 2010). A specific cognitive psychosocial intervention is reminiscence therapy (Grand, et al., 2011; Vernooij-Dassen, et al., 2010). Reminiscence therapy focuses on prompting a person with dementia to think about an event or experience from their past utilizing props and engaging the different senses to help prompt memory (Grand, et al., 2011). This type of therapy helps to improve cognitive functioning, decrease disturbing behaviors, and decrease depressive symptoms in people with dementia (Grand, et al., 2011). The psychosocial intervention of behavioral management may be utilized to improve quality of life and decrease agitation for people with dementia (Barton, et al., 2016; Cohen-Mansfield, 2001; Dyer, et al., 2018; Moniz Cook, et al., 2012). A type of behavior management is called functional analysis based intervention (Dyer, et al., 2018; Moniz Cook, et al., 2012). This therapy focuses on determining the cause or purpose of a disturbing behavior and then implementing a strategy to decrease the disturbing behavior (Moniz Cook, et al., 2012). Psychosocial interventions are an integral part of nonpharmacological treatments as they may improve multiple symptoms of dementia such as cognitive functioning, mood, behaviors, depressive symptoms, and quality of life (Grand, et al., 2011; McDermott, et al., 2018). Since nonpharmacological treatments may improve the lives of people with dementia without the harsh side-effects of pharmacological treatments, it is important to research and develop specific nonpharmacological intervention for people with dementia, such as those provided by

recreational therapists (Barton, et al., 2016; Dyer, et al., 2018; Grand, et al., 2011; McDermott, et al., 2018; Reus, et al., 2016).

Recreational Therapy

Recreational therapy is a healthcare profession and is defined by the American Therapeutic Recreation Association (2015) as,

“a systematic process that utilizes recreation and other activity-based interventions to address the assessed needs of individuals with illness and/or disabling conditions, as a means to psychological and physical health, recovery, and well-being” (American Therapeutic Recreation Association [ATRA] 2015, p. 1).

Recreational therapy is an eclectic therapy, it utilizes approaches and techniques from a variety of sources to best help each client a recreational therapist works with (Austin, 2013). It is by drawing from these resources that a recreational therapist may provide purposeful interventions aimed at achieving the highest possible level of health and quality of life for a client (Austin, 2013; Austin, 2015a). There are approximately 19,000 Certified Therapeutic Recreation Specialists (CTRS) in the United States that may provide recreational therapy services according to the National Council for Therapeutic Recreation Certification (2018). Clients may receive recreational therapy services at many different healthcare settings such as general hospitals, psychiatric hospitals, skilled nursing facilities, assisted living facilities, home healthcare, correctional facilities, rehabilitation centers, and community mental health centers (Austin, 2015a). Most

recreational therapists' work at either a hospital, 38%, or a skilled nursing facility, 19% (National Council for Therapeutic Recreation Certification [NCTRC], 2014).

Recreational therapy services may be beneficial to anyone wanting to recover from an illness or learn to cope with a disability or other chronic condition (Austin, 2015a).

Specific populations recreational therapists treat include behavior/mental health 37%, geriatrics 29%, physical disabilities 20%, and developmental disorders, 14% (NCTRC, 2014). Within these populations, recreational therapists tend to work mostly with adults and/or older adults, 80%, while 14% work with adolescents and/or pediatric, and 13% with all ages (NCTRC, 2014).

Recreational therapists are nationally certified allied healthcare providers. The systematic process they utilize is called Assessment, Planning, Implementing, Evaluating, and Documentation (APIED). The assessment portion of recreational therapy is when the therapist focuses on individualized treatment by determining leisure interests as well as any specific needs of the client (Austin, 2013). The recreational therapist also assesses the client's cognitive and physical abilities to help ensure that the activity selected is appropriate for the individual's level of functioning (Austin, 2013; Kolanowski, Fick, & Buettner, 2009). During planning, the recreational therapist completes an activity analysis of all activities to be done with a client. The activity analysis breaks activities down into a step-by-step process to ensure that the client may perform all aspects successfully (Austin, 2013; Porter, 2016). If a step could not be completed by a client, the recreational therapist then adapts the activity to the ability level of the client while maintaining the activity as close as possible to the original (Kolanowski, et al., 2009). Implementation is

when the recreational therapist and the client work together to achieve the client's goals through the intervention. Recreational therapists may focus on improving the clients' lives in areas such as cognition, emotions, physical and social well-being using various interventions and techniques (Austin, 2013; Kolanowski, et al., 2009). After implementation, an evaluation is often done to document the progress of client goals and/or to determine the efficacy of the intervention chosen for the client (Austin, 2015b). The last part of APIED, documentation, is done throughout the entire process by keeping records of assessments, planning materials, implementation, and evaluations for each client.

Recreational therapy for dementia. Looking more specifically at recreational therapy for people with dementia, there are numerous benefits. Buettner et al. (1996) was one of the first researchers to show the efficacy of recreational therapy in practice for people with dementia. Thirty-six people with dementia and agitation in a nursing home received four weeks of a neurodevelopmental sequencing program from a CTRS and then four weeks of traditional nursing home programs such as bingo, sing-a-longs, crafts, and other social activities (Buettner, et al., 1996). The neurodevelopmental sequencing program included activities such as sensory air mat therapy, sensory stimulation box programs, geriatric exercise/relaxation program, sensory herb garden/adapted garden, and an area for independent leisure pursuits (Buettner, et al., 1996). During the neurodevelopmental sequencing program, the participants received individualized interventions with goals and it was shown to be best at aiding people with dementia decrease boredom and agitation, while also improving strength and flexibility in

comparison to non-recreational therapy traditional nursing home programs (Buettner et al., 1996). In a later study by Buettner and Ferrario (1998), thirty-three people with dementia received a neurodevelopmental sequencing program from CTRS and nursing staff (Buettner & Ferrario, 1998). After thirty weeks of the neurodevelopmental sequencing program, the participants had a greater improvement of cognition and decreased depression than the thirty-three control participants receiving traditional nursing home programs (Buettner & Ferrario, 1998). This further showed that there is a need for structured interventions, such as neurodevelopmental sequencing, that prompt engagement in activities for people with dementia (Buettner & Ferrario, 1998). These types of programs may increase cognitive functioning and decrease depression. It was also one of the first studies to show that nonpharmacological interventions may improve cognition and decrease depression in people with dementia without the use of medications (Buettner & Ferrario, 1998). In response to Buettner et al. 1996, and Buettner and Ferrario 1998, The Dementia Practice Guidelines for Recreational Therapy: Treatment of disturbing behaviors was created by Buettner and Fitzsimmons (2003). This provided a basic framework for recreational therapist to utilize in providing evidence-based practice for their clients. In one of the more recent efficacy studies of recreational therapy, (Buettner, et al., 2006), 107 people with dementia received over 1,800 intervention sessions with 72 different recreational activities over three years at five different long-term care facilities. The recreational therapy interventions were continually able to produce expected results and were efficacious for disruptive behaviors more so than medications intended for disruptive behaviors (Buettner, et al., 2006). There is a

continual need to increase the number of evidence-based programs a recreational therapist can provide to best suit the wants and needs of clients (Bedini, 2009; Buettner & Fitzsimmons, 2003; Buettner, et al., 2006; McCormick & Lee, 2001; Stumbo, 2003). Additionally, there is a need for research on innovative approaches, such as using horticulture activities, and their efficacy in recreational therapy practice (Bedini, 2009; McCormick & Lee, 2001; Stumbo, 2003)

Horticulture as a modality for recreational therapy. Horticultural therapy is a growing field with research and activities that a recreational therapist may utilize in interventions with their clients where it fits the client's needs and interests best (Jarrott, et al., 2002). The therapeutic use of horticulture involves a recreational therapist using a variety of interventions and techniques specifically focused on plant-based activities (Gigliotti et al., 2004; Gigliotti & Jarrott, 2005; Jarrott, et al., 2002). The theoretical basis of using horticulture activities lies in the idea that being in or interacting with the natural world may reduce stress and ill-being (Gigliotti et al., 2004; Kaplan, 1995). Horticulture activities offer many benefits to those who partake in them, especially for people with dementia. They are shown to improve over-all quality of life, increase engagement in activities, decrease disruptive behaviors, and increase positive affect (Barnicle & Midden, 2003; Detweiler, Murphy, Myers, & Kim, 2008; Gigliotti et al., 2004; Gigliotti & Jarrott, 2005; Hall, Mitchell, Webber, & Johnson, 2016; Heliker, Chadwick, & O'Connell, 2001; Jarrott et al., 2002). Besides Kaplan's (1995) work on how nature decreases stress and ill-being, there are additional ideas of why using horticulture activities produces such benefits. Gibson et al. (2007) conducted semi-structured interviews of 10 people with

dementia living in a care home, their 13 family caregivers, and 10 professional caregivers and found that for people with dementia, horticulture activities are something that resonates with them. Being outdoors and engaging with nature tends to be an essential part of life experiences for people with dementia and it has been shown that being outside is something they value (Gibson, Chalfont, Clarke, Torrington, & Sixsmith, 2007). In a study by Heliker et al. (2001), they interviewed 24 community dwelling elders about the meaning of gardening after a three-month structured gardening program and it was found that horticulture was beneficial because they found personal meaning in the activities, enjoyed reminiscing, and experienced spiritual healing. It is more likely that participants will reap additional benefits from the therapeutic use of horticulture since they find such meaning in the activities.

Horticulture activities can be indoors or outdoors depending on preference but facilitating outdoors has additional benefits that may better enable a person with dementia to achieve their psychological needs as well as other goals. The outdoors has a variety of positive impacts on people with dementia. Even just viewing nature increases executive functioning for at least a brief amount of time in older adults (Gamble, Howard Jr, & Howard, 2014) and reflecting about outdoors resulted in a positive affirmation of self by people with dementia (Olsson, Lampic, Skovdahl, & Engström, 2013). If viewing and reflecting on nature is extended to sitting outside, the benefits expand to include decreasing blood pressure and pulse rate, which is beneficial for people with dementia who experience stress due to the symptoms of dementia (Ottosson & Grahn, 2005). Once the step is made from sitting to walking and engaging the outdoors, the benefits grow to

include decreasing agitation and depression, increasing quality of life, well-being, self-esteem, positive emotions, better sleep, and aids in maintaining functional capacity (Connell, et al., 2007; Edwards, McDonnell, & Merl, 2013; Olsson et al., 2013; Rappe & Topo, 2007; Thelander, Wahlin, Olofsson, Heikkilä, & Sonde, 2008). There is ample research to show the benefits of the outdoors for people with dementia and for horticulture activities, but there is a need for research to evaluate the effects of the two together for people with dementia.

There are a variety of activities a recreational therapist could utilize in horticulture to help a client fulfill their psychological needs and improve their well-being. This study will be specifically looking at the use of sensory garden interventions. A sensory garden is a garden that can stimulate all the senses (Gonzalez & Kirkevold, 2014). Participants of sensory garden interventions are often prompted to taste plants that are safe to eat, smell plants, observe what the plant looks like, to listen to leaves rustling in the breeze, and to feel the leaves, flowers, and dirt. This is beneficial in bringing participants into the moment and often results in participants sharing memories and emotions associated with gardening. It is when participants reach this point that they start to fulfill their psychological needs because of gardening with a therapist's guidance. There has been research in the passive use of sensory gardens, such as residents of a nursing facility wandering or participating in unstructured activities, but very little in active, structured activities (Gonzalez & Kirkevold, 2014). In a two-year observational study by Detweiler et al. (2008), 29 residents of a nursing home with dementia were observed for one year prior to an installation of a wandering garden and one year post the installation of a

wandering garden, which is a garden designed to stimulate the senses, like a sensory garden, but with no structured activities to engage the participants. It was found that the wandering garden was effective in decreasing agitation, disruptive behaviors, depression, and increasing quality of life in people with dementia (Detweiler, et al., 2008). Edwards et al. (2013) found the same benefits of decreased agitation, decreased depression, and improved quality of life for 12 residents of a nursing home three months post installation of a wandering garden. In a survey of 302 healthcare workers it was found that healthcare providers see sensory gardens as valuable, but they are mostly used for the passive act of wandering (Gonzalez & Kirkevold, 2015) and the full benefits that a sensory garden intervention could provide are not being obtained. There is a need for more research on the effects of a sensory garden interventions for people with dementia (Buettner & Fitzsimmons, 2003). Even the outdoors in general is beneficial for a person with dementia by reducing the stress response (Ottoosson & Grahn, 2005). While this is promising, the benefits utilizing a sensory garden intervention in recreational therapy practice for people with dementia is unknown. There is a need for research on using sensory gardens for people with dementia.

Theoretical framework

The Theory of Personhood and The Model of Psychological Needs & Well-Being in Dementia. The Theory of Personhood is the idea that a person with dementia has a shattered sense of intersubjectivity, or no intersubjectivity and therefore no sense of personhood (Kitwood, 1992). Personhood is how we relate to others and our status or respect garnered and as inherently social creatures, personhood is required to experience

well-being (Kitwood, 1992). From the Theory of Personhood, The Model of Psychological Needs & Well-Being in Dementia was developed to provide a framework of what dementia care should be. The Model of Psychological Needs & Well-Being in Dementia states that the prime task of dementia care should be to promote the individual in securing their sense of self and personhood (Kaufman, 2016; Kitwood, 1997). The main idea of Kitwood's (1997) Theory of Personhood and Model of Psychological Needs & Well-Being in Dementia is that people with dementia have a core need for love that may be fulfilled by addressing key psychological needs that will maintain their personhood. The key psychological needs were categorized into the domains of comfort, attachment, inclusion, occupation, identity, and agency (Kaufman, 2016; Kitwood, 1997). Comfort can be defined as being provided with empathy, being treated with tenderness, and experiencing closeness (Kitwood, 1997). As a result of fulfilled comfort, a person with dementia may feel strong enough to handle life's challenges (Kitwood, 1997). Recreational therapy helps clients to experience comfort through facilitating positive thoughts, enjoyment, and being empathetic (Austin, 2013). Attachment is the need for specific bonds to people, animals, tasks, or certain objects; the need for attachment is high for people with dementia, since their world is constantly changing, to try and cling to someone or something familiar (Kaufman, 2016; Kitwood, 1997). Inclusion is the need for a person with dementia to be involved and feel accepted in community and in activities with other people (Kaufman, 2016; Kitwood, 1997). Occupation is defined by Kitwood (1997) as having feelings of deep satisfaction and self-esteem through being involved in life in a way that is personally meaningful such as exercise, working,

conversation, reading, listening to the radio, observing others, participating in activities, and resting (Kaufman, 2016; Kitwood, 1997). Occupation is a domain that recreational therapy may easily fill for participants by providing leisure activities where they may find meaning and purpose (Tortosa-Martinez & Yoder, 2015). Identity is the sense of self, having a narrative to tell, being able to maintain a role, lifestyle continuity, feeling healthy, and recognition and acceptance of their feelings (Kaufman, 2016; Kitwood, 1997). Recreational therapy helps a person with dementia to reconnect to their identity by enabling them to continue doing leisure interests to the best of their ability that they enjoyed in the past. The final psychological need of agency is the ability and opportunity to make their own choices, have self-determination, and either actual or perceived independence (Kaufman, 2016). Recreational therapist addresses agency through prompting clients to make their own decisions about treatment and activities pursued during recreational therapy (Austin, 2013). By meeting the psychological needs of a person with dementia, a recreational therapist may help a client to maintain their personhood.

Theory of Supportive Gardens. The Theory of Supportive Gardens is the idea that gardens have the capability to influence healing by providing stress relief and restoration, especially in healthcare settings (Ulrich, 1999). Gardens reduce stress and increase feelings of restoration through four main restorative resources within gardens: a sense of control, social support, opportunity for physical movement and exercise, and access to nature and other distractions (Ulrich, 1999). Gardens provide a sense of control by enabling a patient to make the choice to temporarily escape from the healthcare setting

and other stress aspects of illness (Ulrich, 1999). Social support is seen in gardens as they are important settings for social interaction to occur as they are more natural than a healthcare setting for personally meaningful interactions (Ulrich, 1999). Gardens provide an opportunity for physical exercise and movement in a healthcare setting which then enables the patient to receive the emotional and psychological benefits of exercise such as reduced depression for people with dementia (Ulrich, 1999). Access to nature and other natural distraction enable a patient in a healthcare setting to have a positive distraction that promotes an improved emotional state by blocking negative thoughts and worries (Ulrich, 1999).

The intermeshing of theories. The Theory of Supportive Gardens shows that using horticulture in interventions may be beneficial in fulfilling the psychological needs of agency, identity, inclusion, comfort, and attachment as identified by Kitwood (1997). Gardening fulfills agency through the sense of control it provides to participants when they can care for something outside themselves. People with dementia are often forced to be dependent upon others instead of being the independent person they have been for most of their life. Gardening reverses their role back into the caretaker helping them to solidify or reassure them of their identity. By prompting a client with dementia to get involved in gardening to the best of their ability with other people, a recreational therapist may aid the participant in gaining a sense of inclusion and therefore help them feel better connected to the people around them. Gardening is something people with dementia may find meaning and purpose in as they take care of another living thing and make connections to other people, evidenced by the increase in participation and engagement

that is seen in horticulture activities (Gigliotti et al., 2004; Gigliotti & Jarrott, 2005; Hall et al., 2016; Jarrott et al., 2002). The Theory of Supportive Gardens states that access and involvement in nature decreases stress by providing a distraction from thoughts, and reducing blood pressure and stress hormones (Ottosson & Grahn, 2005; Ulrich, 1999). The decrease in stress gives a participant in horticulture activities a sense of comfort that promotes their quality of life. These natural distractions also provide a place for feelings of attachment since many people with dementia are from a generation that being outside and in nature was a big part of their life experiences (Gibson et al., 2007).

Recreational therapy may integrate the Theory of Personhood and The Model of Psychological Needs & Well-Being in Dementia with the Theory of Supportive Gardens to provide the best treatment for a client with dementia. In a study done by Hall et al. (2016), the link between recreational therapy, the Theory of Personhood and The Model of Psychological Needs & Well-Being in Dementia, and the Theory of Supportive Gardening is best seen. Hall et al. (2016) had 14 participants with dementia do structured horticulture activities for ten weeks twice a week for an hour each week. They selected participants based on diagnosis of dementia and a past interest in gardening activities and a recreation team carried out the structured activities. At the end of the experiment, Hall et al. (2016) found that the participant interview results reflected Kitwood's (1997) Theory of Personhood and The Model of Psychological Needs & Well-Being in Dementia. There was a theme of experiencing relaxation and restfulness in the garden reported by the participants, which relates to Kitwood's area of comfort. Identity was found in the participants during the activities as they were each seen to bring their own

personality to the horticulture activities. Hall et al. (2016) also noted that the participants achieved occupation from working outside and inclusion because the residents each had their own area to tend and manage. Finally, attachment developed in the participants over time from continuing to care for their garden for ten weeks (Hall et al., 2016). From this, it may be concluded that the Theory of Supportive Gardening might fit into the Theory of Personhood and The Model of Psychological Needs & Well-Being in Dementia since it was the horticulture activities that resulted in the participants obtaining their psychological needs. An additional study looked at the effects of horticulture activities on the cognitive functioning of people with Alzheimer's, a type of dementia (D'Andrea, Batavia, & Sasson, 2007). D'Andrea et al. (2007) did gardening activities conducted by a recreational therapist over twelve weeks and the participants were found to have maintenance of memory abilities, improvement in cognitive functioning, and an increase in well-being (D'Andrea, et al., 2007). There is need for further research to validate these claims and for the integration of horticulture activities into recreational therapy practice.

CHAPTER 3

Methods

This study used a multiple treatment single-subject design (A_1 -B-BC- A_2) to examine the impact of a sensory garden intervention on agitation and quality of life in people with dementia. Participants were selected from a local nursing home and data were collected on their demographics, agitation, cognition, and quality of life.

Single-Subject Design

Single-subject design is a research method that focuses on a few subjects at a time to gather in depth information (Dattilo, Gast, Loy, & Malley, 2000; Riley-Tillman & Burns, 2009). The general philosophy of single-subject design is to look at change at the individual level instead of group levels since group levels could be misleading when applied to the individual in practice (Barlow, Nock, & Hersen, 2009). Subjects in single-subject design often act as their own control through establishing baselines, where subjects are measured on the behavior in question prior to any intervention for a specific time or until scores from measurements are consistent (Barlow, et al., 2009). Single-subject design is useful in determining the effect an intervention has on specific behaviors for subjects of interest (Dattilo, et al., 2000).

Single-subject design provided numerous benefits for this study. Fewer subjects enabled the researcher to focus more on clinical significance than statistical significance. Clinical significance is when the effects of an intervention results in change to the target behavior that is determined meaningful to the individual by the researcher based on their extensive knowledge of behavior and interpretation of the data (Barlow, et al., 2009). If

one participant improves significantly then the characteristics of that participant could be looked at and a practitioner could generalize the results of the study to a client of theirs with similar characteristics (Barlow, et al., 2009). In the A₁-B-BC-A₂ design of this study, A₁ is the baseline, B is an intervention (indoor sensory garden), and BC (approximated outdoor sensory garden) is the same intervention with only one variable different than B, and the final A₂ is a return to baseline.

Procedure

Recruiting. Participants were recruited from the memory care center of a local nursing home. The activities coordinator identified residents who fulfilled the inclusion criteria to the researcher and were interested in participating. An informed consent letter was sent to obtain family consent. Then residents, with family consent, were asked if they would want to participate in a sensory garden for eight weeks to potentially reduce agitation and improve quality of life.

Inclusion/exclusion criteria. To be eligible to participate in the study, individuals must have met the following inclusion criteria: 1) diagnosis of dementia; 2) identified current or previous interest in gardening; 3) stable on current medications; and 4) five documented disruptive behaviors and/or a period of agitation by a formal caregiver within the past two weeks. Potential participants were excluded from the study if there was a known reason they would be unable to participate in sessions three times a week for 30-45 minutes, such as scheduled therapy.

Site information. This study was conducted at a continuing care retirement community. It offered independent living, assisted living, skilled nursing, and memory

care. Participants for this study resided in the memory care center of the nursing home. The memory care center is two stories with the second floor having residents with earlier stages of dementia and the first floor for those with more progressive dementia; at capacity there are sixteen residents on each floor. It has a purpose-built design that helps to orient and decrease stress for residents. It also features private dining rooms for each floor, access to a beauty salon, two covered porches, and an enclosed courtyard and garden area. All residents have an individualized care plan, private rooms, daily activities, physical therapy, occupational therapy, and speech therapy if needed, and daily supervision by a registered nurse and memory care team. They utilize the Positive Approach to Care™ by Teepa Snow to provide their care, they focus on adapting to a person with dementia individual needs and using their remaining strengths (Teepa, 2018).

Intervention. Participants were in baseline A₁ for two weeks, followed by intervention B for four weeks, then intervention BC for four weeks, and lastly they returned to baseline A₂ for two weeks. Interventions lasted 30-45 minutes three times a week. The only difference between intervention B and BC was the setting of the intervention. The sessions were the same every time.

Intervention B was an indoor sensory garden, held in the dining room/common area on the first floor of the memory care center. On a typical day there were people walking around, dishes being washed in the nearby kitchen and the television on in the living room about 15 feet away. The sensory garden was on top of a dining table so that participants could sit and participate in the indoor sensory garden. All intervention B and BC sessions were the same and in the mid-morning.

Intervention BC was an approximated outdoor sensory garden. An approximated outdoor sensory garden was used instead of an outdoor sensory garden because of a delay in the start of the study that led to outside temperatures too cold for participants to go outside and garden. The indoor sensory garden was modified into an approximated outdoor sensory garden by creating an environment secluded from the daily activities in the common area. This was done by having a canopy tent with curtains separate the sensory garden from the common area visually as well as aid in dampening sounds. The approximated outdoor sensory garden was constructed by a wall of windows to allow natural light in and to provide nature views. The combination of removing the participants from their typical environment into the brightly lit approximated outdoor sensory garden with nature views and fewer distractions was determined to be the best approach to mimic an outdoor scenario. All intervention BC and B sessions were the same and in the mid-morning.

At each session, the participants engaged in the sensory garden interventions with guidance from the researcher. When participants arrived at the intervention location, the researcher greeted each resident followed by a reminder that they will be participating in a sensory garden for the next 30-45 minutes. The researcher invited the participants to engage with the plants in the sensory garden. The researcher asked the participants to describe what the plants looked like and if the plants remind them of other objects or memories. The researcher then asked them to touch the plants and describe what they felt and asked if they felt specific aspects of the plants, such as their texture or temperature. Next, the participants were asked if feeling the plants remind them of other objects or of

memories. After each participant shared, the researcher asked them to smell each plant and to share memories that could be associated with that specific plant. While engaging with the plants, the participants were asked to describe what the plants sounded like by crushing leaves or petals near their ears or listening to the plants when there was a breeze. Lastly, the participants were asked to describe what they think the plant would taste like and to then taste some of the plants (all plants in the intervention were non-toxic). The researcher asked if they have eaten other things that taste similar or if the taste reminded them of a certain food they enjoy. After engaging all the senses, the researcher then thanked the participants for their participation and helped them get to their next activity or desired location.

The sensory garden consisted of Cilantro (*Coriandrum Sativum*), Simpson Elite Lettuce (*Lactuca sativa* 'Simpson Elite'), Patriot Hosta (*Hosta* 'Patriot'), Rosemary (*Rosmarinus officinalis*), Red Giant Mustard (*Brassica juncea* 'Red Giant'), Yellow Mums (*Chrysanthemum* spp.), and Dracaena (*Dracaena deremensis*). These plants were selected to prevent poisoning from accidental ingestion and can stimulate touch, taste, smell, hearing, and sight. The Red Giant Mustard, Patriot Hosta, and Yellow Mums are good plants to stimulate sight because of the purple of the Red Giant Mustard, white and green contrast of the Patriot Hosta, and the Mum's bright colors. Rosemary, Yellow Mums, Patriot Hosta, Dracaena, and Red Giant Mustard were used to stimulate touch with the bristle texture of Rosemary, velvety texture of Mum flowers, silky texture of Patriot Hosta and the Dracaena, and the leathery texture of the Red Giant Mustard. For smell, Rosemary, Cilantro, and Yellow Mums were used because of the strong odor they

produce. Hearing was stimulated using the Simpson Elite Lettuce and the leaves of the other plants. Lastly, taste was stimulated with Rosemary, Cilantro, and the Simpson Elite Lettuce. The sensory garden was contained in pots, so the same sensory garden was used for both intervention B and BC.

Data Collection

Data were collected on multiple aspects of the participants. Demographic information was obtained from each participant. Agitation was measured using the Agitated Behavior Mapping Instrument (ABMI) and the Cohen-Mansfield Agitation Inventory (CMAI). Additionally, participants' quality of life was measured using the Dementia Quality of Life (DEMQOL) questionnaire. Field notes were also taken during interventions to note anything out of the ordinary and were completed after each intervention session. Field notes included who attended the intervention, who observed the participants, general notes about the environment, unusual occurrences, participant engagement in interventions, and session start and end times. Additionally, the researcher became familiar with the participants behavior and the facility prior to the start of the study by volunteering at the nursing home in the weeks before the study.

Demographics. Demographic information, such as age, gender, race, and diagnoses was obtained about the participants in this study from the nursing home's records and family members.

Agitation. Agitation was measured using the Agitated Behavior Mapping Instrument (ABMI) and the Cohen-Mansfield Agitation Inventory. The ABMI assessed

agitation for each session and the CMAI assessed agitation over the time span of two weeks.

Agitated Behavior Mapping Instrument. Participants were assessed using the Agitated Behavior Mapping Instrument (ABMI). It is used to systematically observe and define the behavior of nursing home residents. This assessment has six sections: behavior, direction and social environment, sleep pattern, location of subject, activity, and environment. This study used the behavior section of the ABMI to measure the number of times verbal non-aggressive behavior, physical non-aggressive behavior, verbal aggressive behavior, and physical aggressive behavior occurred in participants as observed by the researcher during a three-minute window. Thirty different observable behaviors listed on the ABMI were recorded in these categories over the three minutes and then totaled. All observable behaviors on the ABMI had been found to have an average interrater reliability of 0.93 (Cohen-Mansfield, Werner, & Marx, 1989b).

The purpose of using the ABMI was to investigate if disruptive behavior was impacted by the study and if the indoor or the approximated outdoor sensory garden impacted behavior most. During baseline phases A₁ and A₂, participants were unobtrusively observed (standing out of line of sight and not directing their behavior) three days a week with three observational periods a day 30 minutes apart during the same time frame as the intervention was conducted. Having the observations three times a day at the same time as the intervention was to aid in ensuring environmental variables are the same during intervention as in baseline to get the most accurate representation of the participant in daily life. During intervention phases B and BC, ABMI observations

were recorded 30 minutes prior to the intervention, during the intervention, and 30 minutes after the intervention. The 30-minute interval ensures that observations are evenly spread out and not clustered.

Additionally, the ABMI manual was referred to by the researcher and other research team members prior to and during the study to ensure behaviors observed were properly identified and itemized on the form (Cohen-Mansfield, et al., 1989b). Inter-rater reliability was also determined for the researcher and the research team members that assisted with conducting ABMI observations by having observed the same participant and finding the point by point agreement ratio between the researcher and other team members. This was done by counting the instances of agreement and dividing it by the sum of agreements and disagreements. This number was then converted into a percentage by multiplying by 100 giving the percent agreement. This was done until every research team member matched the researcher by at least 90% to ensure inter-rater reliability. After each day of observations, the raw data were entered in Microsoft Excel. Overall, each participant had 108 different observational periods of notes with the AMBI.

Cohen-Mansfield Agitation Inventory. The Cohen-Mansfield Agitation Inventory (CMAI) can be used to assess the frequency of agitated behavior in older adults (Cohen-Mansfield, et al., 1989a). The CMAI short form was used to measure the frequency of agitated behaviors over the past two weeks for each participant. The short form was chosen because it has 14 items in comparison to 29 on the long form and only takes 10 minutes to complete thereby reducing caregiver strain (Cohen-Mansfield, et al., 1989a). The CMAI scores were recorded every two weeks by interviewing a caregiver of

each participant, the same one each time (if possible). It looked at the effect of the intervention over the span of two weeks. This further established the frequency of agitated behaviors of life outside of intervention times for each participant. The data were graphed next to ABMI scores for each participant.

The CMAI short form has 14 items of agitated behavior that can be marked one to five in frequency over the past two weeks with one being never and five very frequent. The CMAI short form has an inter-rater reliability of exact agreement = .82; and 0-1 point discrepancy = .93 (Werner, Cohen-Mansfield, Koroknay, & Braun, 1994). To ensure fidelity of results, an evaluation of the administration of the CMAI was conducted by having the principal investigator review a video of a CMAI interview using the questionnaire in the CMAI manual.

Quality of Life. The Six Item Screener was used to determine the cognitive abilities of participants to determine the appropriate quality of life assessment. Quality of life was assessed using the Dementia Quality of Life-Proxy (DEMQOL-Proxy). All participants were assessed using the Proxy version of the Dementia Quality of Life assessment due to cognitive impairments that limited their ability to self-report quality of life.

Six Item Screener. The Six-Item Screener (SIS) is used to screen for cognitive impairment (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002). It asks test takers to recall three items and three temporal orientations: day of week, month, and year (Callahan, et al., 2002). Time disorientation is specific indicator of people experiencing dementia. Item recall is a good indicator of new learning ability and is a good indicator of

cognitive impairment with high sensitivity (Callahan, et al., 2002). This assessment was selected because it is unobtrusive, short (1-2 minutes), and is considered the gold standard diagnosis of dementia (Callahan, et al., 2002). The SIS was scored by summing up the correct responses, with a score range of zero to eight. A score of four or less indicated a cognitive impairment and the DEMQOL-Proxy was utilized for this individual. The SIS score was noted on the demographic information template for each participant.

Dementia Quality of Life/ Dementia Quality of Life-Proxy. Dementia Quality of Life (DEMQOL) questionnaire is used to measure health-related quality of life for people with dementia (Smith, et al., 2005). It has 28 items and is answered on a scale with four options: a lot, quite a bit, a little, and not at all. Within these items, the DEMQOL addresses five domains: daily activities and looking after yourself, health and well-being, cognitive functioning, social relationships, and self-concept. This study used this assessment to analyze quality of life. This questionnaire was also selected because it has internal consistency of 0.87 and test-retest reliability of 0.84 for people with mild to moderate dementia ($SIS \geq 4$) (Smith, et al., 2007; Smith, et al., 2005).

The DEMQOL is only recommended for people with dementia who score above a four on the SIS (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002). Scores of less than four indicate the need to administer the Dementia Quality of Life-Proxy (DEMQOL-Proxy). The DEMQOL-Proxy utilizes the same conceptual framework as the DEMQOL but has 31 items and is conducted by interviewing a caregiver of the person with dementia. This questionnaire was shown to have internal consistency reliability of 0.87

for people with mild to moderate dementia and 0.92 with severe dementia and test-retest reliability of 0.67 for mild to moderate dementia and 0.84 for severe dementia (Smith, et al., 2007).

Based on participants' SIS scores, the DEMQOL-Proxy was conducted every week for all participants. Caregivers were interviewed by the researcher or a research assistant following the guidelines in the interviewer manual (Smith, et al., 2005) at the end of every week. The DEMQOL-Proxy was scored one to four with one being a lot and four not at all, except for items with asterisks which are to be reverse scored (Smith, et al., 2005). Once totaled, the higher the score the better their quality of life (Smith, et al., 2005).

Data Analysis

General considerations. The use of visual analysis in single subject design enables the researcher to analyze point by point the effect of a particular portion of the intervention on a participant (Tawney & Gast, 1984). It also allows for the researcher to determine whether the intervention has a clinically significant effect on the participant by seeing all the data (Tawney & Gast, 1984). Demographic data were analyzed using descriptive statistics and frequencies. Using the guidelines from Tawney and Gast (1984), data from assessments were analyzed qualitatively by visually comparing line graphs of ABMI observations, CMAI scores, and DEMQOL-Proxy scores. Using line graphs, data were visually analyzed by looking at the change between phase, and within phases to determine if an intervention was effective or not effective based on data points either increasing (quality of life) or decreasing (agitation) when starting a new phase and

throughout a phase. For people with dementia, decline in quality of life and an increase in agitation is expected with the progression of the condition, therefore no change in scores/observations during either intervention B or BC was determined effective. Clinical significance was found when the effects of an intervention resulted in change to the target behavior that was determined meaningful to the individual by the researcher, based on their extensive knowledge of behavior and their visual interpretation of line graphs for each participant during the study.

The goal of this study was to determine the impact of a sensory garden on disruptive behaviors and quality of life for people with dementia. By looking at the types of disruptive behaviors and during what phase they occur the most and least it may be determined if interventions were beneficial to participants, and if intervention B or BC worked better. It also determined if the interventions have effects lasting over two weeks as indicated by visual interpretation of the line graphs.

Agitation.

ABMI. The behavior section of the ABMI was analyzed based on the sub-types of agitated behavior: verbal non-aggressive behavior, physical non-aggressive behavior, verbal aggressive behavior, and physical aggressive behavior. Each participant had three different observational periods per a session day. Individual items on the ABMI were averaged across the three observational times each session day. These item averages were then summed for the sub-types of behaviors to represent that behavior for the session day. The average of the three observations each day for each four sub-types of behavior were graphed for each participant and analyzed using visual analysis.

The ABMI assessment was the only assessment with missing data due to participants not present during an observational period. Missing data were assumed to be missing at random with multivariate normality and were handled using Full Information Maximum Likelihood (FIML). FIML takes into consideration all the data when running the likelihood function. The AMBI behavior section for all participants was input into Microsoft Excel with each of the thirty items from every observational window in its own cell. Having the data split up by items instead of averages reduced the potential for error. Once FIML was conducted, data analysis was conducted using visual analysis.

CMAI. The CMAI short form was scored for each factor: aggressive behavior, physically nonaggressive behavior, and verbally aggressive behavior and then averaged. CMAI scores were then graphed for each participant to give a visual representation of the data. The lower the score the less agitation they experienced in the past two weeks. These scores were used to determine if the intervention influenced the participants outside of the intervention time frame when the researcher could not observe the participants. The graphs were then used to visually analyze the data and determine clinical significance.

Quality of Life. DEMQOL-Proxy scores for each week were placed onto a line graph for each participant to determine the impact of the study on quality of life of participants and if intervention B or BC resulted in significant increases. The higher the score, the greater quality of life for the participant. The graphs were then visually analyzed to determine clinical significance.

CHAPTER 4

MANUSCRIPT 1

THE IMPACT OF A SENSORY GARDEN FOR PEOPLE WITH DEMENTIA

THE IMPACT OF A SENSORY GARDEN
FOR PEOPLE WITH DEMENTIA

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Abstract

The purpose of this study was to determine the impact of sensory garden interventions on agitation and quality of life for people with dementia. The sensory garden consisted of plants that stimulated all the senses. Four people diagnosed with dementia residing in assisted living participated in the multiple treatment single-subject design (A₁-B-BC-A₂) study. Baseline phase A₁ lasted two-weeks, intervention B and BC were four-weeks each, and return to baseline A₂ was two-weeks, for a total of 12 weeks. Intervention B was an indoor sensory garden and intervention BC was an approximated outside sensory garden. Data revealed positive trends following the sensory garden interventions on decreasing agitation and improving quality of life. Intervention B worked best for two participants and intervention BC for the remaining two participants. Applications to recreational therapy practice are provided.

Keywords: recreational therapy, sensory garden, dementia, agitation, quality of life

Introduction

Dementia is a neurocognitive disorder primarily consisting of progressive cognitive decline (Tortosa-Martinez & Yoder, 2015). Dementia typically affects people later in life but may also start earlier (Tortosa-Martinez & Yoder, 2015). There is an increasing number of people living over the age of 65 years, and therefore an expected rise in the current population of people living with dementia, approximately 35.6 million people in the world, doubling every 20 years (Prince, Bryce, Albanese, Wimo, Ribeiro, & Ferri, 2013).

The effects of dementia are varied and dramatic. Dementia-related cognitive decline includes difficulty with memory, executive functioning, attention, and independence (Buettner, Lundedren, Lago, Farrell, & Smith, 1996). This decline hinders the ability to participate in work, community life, and socializing (Buettner, et al., 1996). In the later stages of dementia, individuals may experience agitation and disruptive behaviors (Kales, Gitlin, & Lyketsos, 2015), which may lead to removal from activities, isolation, and additional hospitalizations (Beuttner, et al., 1996; Kales, et al., 2015).

There is currently no cure for dementia (Buckley & Salpeter, 2015; Grand, Caspar, & MacDonald, 2011). Pharmacological treatments available (such as Cholinesterase inhibitors and atypical antipsychotics) are not recommended for most people with dementia, as the short-term gains do not outweigh the negative side-effects (Buckley & Salpeter, 2015; Reus, et al., 2016). Therefore, the most common and recommended treatments for people with dementia are nonpharmacological (Grand, et al., 2011; Kales, et al., 2015; Reus, et al., 2016; Salzman, et al., 2008), and include

environmental adaptations, caregiver training, and psychosocial interventions (Barton, Ketelle, Merrilees & Miller, 2016; Buettner, Fitzsimmons, & Atav, 2006; Dyer, Harrison, Laver, Whitehead & Crotty, 2018; Grand, et al., 2011; McDermott, et al., 2018; Moniz Cook, De Vugt, Verhey & James, 2012; Salzman, et al., 2008).

The field of recreational therapy (RT) may provide numerous benefits for a person with dementia. In a large efficacy study of RT (Buettner, et al., 2006), the RT interventions were efficacious for disruptive behaviors more so than medications intended for disruptive behaviors (Buettner, et al., 2006). One intervention appropriate for use in RT is a sensory garden, a garden that is used to stimulate touch, taste, sight, smell, and hearing (Gonzalez & Kirkevold, 2014). When a person engages all their senses, they are brought into the moment because of the focused attention on their current environment and actions, which leads to fulfilling their psychological needs. For people with dementia, horticulture activities are shown to improve overall well-being, increase engagement in activities, decrease disruptive behaviors, and increase positive affect (Barnicle & Midden, 2003; Detweiler, Murphy, Myers, & Kim, 2008; Gigliotti et al., 2004; Gigliotti & Jarrott, 2005; Hall, Mitchell, Webber, & Johnson, 2016; Heliker, Chadwick, & O'Connell, 2001; Jarrott et al., 2002).

Two theories provide support for using a sensory garden intervention in RT practice. First, the Theory of Personhood states that a person with dementia struggles to maintain their intersubjectivity (i.e., ability to understand oneself based on how oneself relates to people and they relate to oneself), therefore losing their personhood (Kitwood, 1992). This theory further states that to reclaim their intersubjectivity, a person with

dementia needs to fulfill the psychological needs of comfort, attachment, inclusion, occupation, and agency (Kitwood, 1992; Kitwood, 1997; Kaufman, 2016). The Theory of Supportive Gardens states that the four main functions of a garden in a healthcare setting are to provide stress relief and restoration through a sense of control, social support, physical movement and exercise, and access to nature and other positive distractions (Ulrich, 1999). These theories work together to support the concept of using a sensory garden. A garden is an essential environment to experience comfort, attachment to leisure interests, inclusion into social interactions and activities, a sense of agency from being able to make the choice to seek a temporary escape from the healthcare setting. When a person with dementia experiences comfort, attachment, inclusion, and agency they will likely experience a higher level of intersubjectivity and therefore improved well-being. Therefore, the purpose of this study was to determine the impact of sensory gardens on people with dementia, specifically their agitation and quality of life.

Methods

A multiple treatment single-subject design (A_1 -B-BC- A_2) was used to examine the impact of utilizing a sensory garden intervention on agitation and quality of life in people with dementia, and this study was approved by the local institutional review board. Multiple treatment design enabled the researcher to isolate the independent variable to determine it as the source of experimental results ensuring the validity of results (Barlow, et al., 2009). In the A_1 -B-BC- A_2 design of this study, A_1 was the baseline, B was an intervention, and BC was the same intervention with only one variable different than B, followed by return to baseline A_2 .

Procedure

To participate in the study, individuals must have met the following inclusion criteria: 1) have a diagnosis of dementia; 2) identified current or previous interest in gardening; 3) stable on current medications; and 4) five documentations of disruptive behavior and/or a period of agitation by a formal caregiver within the past two weeks. Potential participants were excluded from the study if there was a known reason they would be unable to participate in sessions three times a week.

This study was conducted at a continuing care retirement community in the memory care center. This facility utilizes the Positive Approach to Care™ by Teepa Snow to provide their care, they focus on adapting to a person with dementia's individual needs and using their remaining strengths (Teepa, 2018). The Activities Coordinator identified six residents who fulfilled the inclusion criteria and were interested in participating. They then handed or mailed an informed consent letter to the resident's family to obtain family consent. Then residents, with family consent, were asked if they would want to participate in a sensory garden for eight weeks to potentially reduce agitation and improve quality of life. Of the six people approached to be in the study, four individuals assented and their families consented.

Intervention

Participants were in baseline A₁ for two weeks, followed by intervention B for four weeks, then intervention BC for four weeks, and lastly they were in return to baseline A₂ for two weeks. Interventions lasted 30-45 minutes three times a week. The

only difference between intervention B and BC was the setting of the intervention. All intervention B and BC sessions were the same and in the mid-morning.

Intervention B, the indoor sensory garden was held in the dining room/common area on the first floor of the memory care center. On a typical day there were people walking around, dishes being washed in the nearby kitchen and the television on in the living room about 15 feet away. The sensory garden was on top of a dining table so that participants could sit and participate in the indoor sensory garden. The approximated outdoor sensory garden also took place in the dining room/common area on the first floor of the memory care unit. An approximated outdoor sensory garden was used instead of an outdoor sensory garden because of a delay in the start of the study that led to outside temperatures too cold for participants to go outside and garden. The indoor sensory garden was modified into an approximated outdoor sensory garden by creating an environment secluded from the daily activities in the common area. This was done by having a canopy tent with curtains separate the sensory garden from the common area visually as well as aid in dampening sounds. The approximated outdoor sensory garden was constructed by a wall of windows to allow natural light in and to provide nature views. The combination of removing the participants from their typical environment into the brightly light approximated outdoor sensory garden with nature views and fewer distractions was determined to be the best approach to mimic an outdoor scenario.

When participants arrived at the intervention location, the researcher greeted each resident followed by a reminder that they will be participating in a sensory garden for the next 30-45 minutes. The researcher invited the participants to engage with the plants in

the sensory garden going through the all the senses with the plant in front of them and then switching plants until everyone had each plant at least once. The order of senses for each session was sight, touch, smell, sound, and taste. After going through all the senses, the researcher then thanked the participants for their participation and helped them get to their next activity or desired location.

The sensory garden consisted of Cilantro (*Coriandrum sativum*), Simpson Elite Lettuce (*Lactuca sativa* 'Simpson Elite'), Patriot Hosta (*Hosta* 'Patriot'), Rosemary (*Rosmarinus officinalis*), Red Giant Mustard (*Brassica juncea* 'Red Giant'), Yellow Mums (*Chrysanthemum* spp.), and Dracaena (*Dracaena deremensis*). These plants were selected to prevent poisoning from accidental ingestion and stimulate touch, taste, sight, smell, and hearing. The sensory garden was contained in pots, so the same sensory garden was used for both intervention B and BC.

Data Collection

Demographics. Demographic information, such as age, gender, race, and diagnoses was obtained about the participants in this study from the nursing home's records and family members. Additionally, the researcher became familiar with the participants prior to the start of the study by volunteering at the nursing home in the weeks before the study.

Agitation. Agitation was measured using the Agitated Behavior Mapping Instrument (ABMI) and the Cohen-Mansfield agitation inventory (CMAI). The ABMI assessed agitation for each session and the CMAI assessed agitation over the time span of two weeks. dem

Agitated Behavior Mapping Instrument. The purpose of using the Agitated Behavior Mapping Instrument (ABMI) was to investigate if disruptive behavior was impacted by the study and if it was the indoor (intervention B) or the approximated outdoor sensory garden (intervention BC) that impacted behavior most. This assessment has six sections: behavior, direction and social environment, sleep pattern, location of subject, activity, and environment. This study used the behavior section of the ABMI. The ABMI behavior section was used to measure the number of times verbal non-aggressive behavior, physical non-aggressive behavior, verbal aggressive behavior, and physical aggressive behavior occurred in participants as observed by the researcher during a three-minute window. Thirty different observable behaviors listed on the ABMI was recorded in these categories over the three minutes and then totaled. All observable behaviors on the ABMI had been found to have an average interrater reliability of 0.93 (Cohen-Mansfield, Werner, & Marx, 1989b).

During baseline phases A₁ and A₂, participants were unobtrusively observed (standing out of line of sight and not directing their behavior) three days a week with three observational periods a day 30 minutes apart during the same time frame as the intervention was conducted.. Having the observations three times a day at the same time as intervention phases B and BC was to ensure environmental variables are the same or similar to get the most accurate representation of the participant in daily life. During intervention phases B and BC, ABMI observations were recorded 30 minutes prior to the intervention, during the intervention, and 30 minutes after the intervention. Inter-rater reliability between the researcher and research team members was found to be 0.94.

Cohen-Mansfield Agitation Inventory. The Cohen-Mansfield Agitation Inventory (CMAI) is used to assess the frequency of agitated behavior in older adults (Cohen-Mansfield, et al., 1989a). The CMAI short form was used to measure the frequency of agitated behaviors over the past two weeks for each participant. The short form was chosen because it has 14 items in comparison to 29 on the long form and only takes 10 minutes to complete thereby reducing caregiver strain (Cohen-Mansfield, et al., 1989a). The CMAI scores were recorded every two weeks by interviewing a caregiver of each participant. The CMAI short form has 14 items of agitated behavior that can be marked one to five in frequency over the past two weeks with one being never and five very frequent. The CMAI short form has an inter-rater reliability of exact agreement = .82; and 0-1 point discrepancy = .93 (Werner, Cohen-Mansfield, Koroknay, & Braun, 1994).

Quality of Life. The Six Item Screener was used to determine the cognitive abilities of participants to then select the appropriate quality of life assessment. Quality of life was assessed using the Dementia Quality of Life-Proxy. All participants were assessed using the Proxy version of the Dementia Quality of Life assessment due to cognitive impairments that limited their ability to self-report quality of life.

Six Item Screener. The Six-Item Screener (SIS) was used to determine the appropriate quality of life assessment for a participant based on their cognitive abilities. It is used to screen for cognitive impairment (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002). A score of four or less indicates cognitive impairment and the Dementia Quality of Life-Proxy was utilized for this individual. The SIS asks for test takers to

recall three items and for three temporal orientations: day of week, month, and year (Callahan, et al., 2002). This assessment was selected because it is unobtrusive, short (1-2 minutes), and is considered the gold standard diagnosis of dementia (Callahan, et al., 2002). The SIS was scored by summing up the correct responses, with a score range of zero to eight. The SIS score was noted on the demographic information template for each participant. All participants scored a four or less on the SIS meaning the Dementia Quality of Life-Proxy was used to assess quality of life for all participants (Callahan, et al., 2002).

Dementia Quality of Life/ Dementia Quality of Life-Proxy. Dementia Quality of Life (DEMQOL) questionnaire is used to measure health-related quality of life for people with dementia (Smith, et al., 2005). This study used this assessment to analyze quality of life. The DEMQOL is only recommended for people with dementia who score above a four on the SIS, below a four the Dementia Quality of Life-Proxy (DEMQOL-Proxy) should be administered. All participants were assessed with the DEMQOL-Proxy. It utilizes the same conceptual framework as the DEMQOL but has 31 items instead of 28 and is conducted by interviewing a caregiver of the person with dementia. The DEMQOL-Proxy was scored one to four with one being a lot and four not at all, except for items with asterisks which are to be reverse scored (Smith, et al., 2005). Once totaled, the higher the score the better their quality of life (Smith, et al., 2005). This DEMQOL-Proxy was shown to have internal consistency reliability of 0.87 for people with mild to moderate dementia and 0.92 with severe dementia and test-retest reliability of 0.67 for mild to moderate dementia and 0.84 for severe dementia (Smith, et al., 2007). Caregivers

were interviewed by the researcher or a research assistant for the DEMQOL-Proxy following the guidelines in the interviewer manual (Smith, et al., 2005) at the end of every week.

Data Analysis

General Considerations. Demographic data were analyzed using descriptive statistics and frequencies. Using the guidelines from Tawney and Gast (1984), data from assessments were analyzed qualitatively by visually comparing line graphs of ABMI observations, CMAI scores, and DEMQOL-Proxy scores. Using line graphs, data were visually analyzed by looking at the change between phase, and within phases to determine if an intervention was effective or not effective based on data points either increasing (quality of life) or decreasing (agitation) when starting a new phase and throughout a phase. For people with dementia, decline in quality of life and an increase in agitation is expected with the progression of the condition, therefore no change in scores/observations during either intervention B or BC was determined effective.

The goal of this study was to determine the impact of a sensory garden on disruptive behaviors and quality of life for people with dementia. By looking at the type of disruptive behaviors and during what phase they occur the most and least it may be determined if interventions were beneficial to participants, and if one intervention worked better than the other. It was also determined if the interventions have effects lasting over two weeks as indicated by visual analysis.

Agitation.

ABMI. The behavior section of the ABMI was analyzed based on the sub-types of agitated behavior: verbal non-aggressive behavior, physical non-aggressive behavior, verbal aggressive behavior, and physical aggressive behavior. Each participant had three different observational periods per a session day. Individual items on the ABMI were averaged across the three observational times each session day. These item averages were then summed for the sub-types of behaviors to represent that behavior for the session day. The average of the three observations each day for each four sub-types of behavior were graphed for each participant and analyzed using visual analysis.

The ABMI assessment was the only assessment with missing data due to participants not present during an observational period. Missing data was assumed to be missing at random with multivariate normality and were handled using Full Information Maximum Likelihood (FIML). FIML takes into consideration all the data when running the likelihood function. The AMBI behavior section for all participants was input into Microsoft Excel with each of the thirty items from every observational window in its own cell. Splitting the data by items instead of averages reduced the potential for error. Once FIML was conducted, data analysis was conducted visually.

CMAI. The CMAI short form was scored for each factor: aggressive behavior, physically nonaggressive behavior, and verbally aggressive behavior and then averaged. CMAI scores were then graphed for each participant to give a visual representation of the data. The lower the score the less agitation they experienced in the past two weeks. These scores were used to see if the intervention influences the participants outside of the

intervention time frame when the researcher could not observe the participants. The graphs were then used to visually analyze data to determine clinical significance.

Quality of Life.

The DEMQOL-Proxy. DEMQOL-Proxy scores for each week were placed onto a line graph for each participant to determine the impact of the study on quality of life of participants and if intervention B or BC resulted in significant increases. The higher the score the greater quality of life for the participant. The graphs were then used to visually analyze data to determine clinical significance.

Results

Four participants completed the 12-week study. They all lived in the memory care unit of a continuum of care retirement center and had a previous interest in gardening as identified by the Activities Coordinator.

Participants

“Daisy,” a 77-year-old white female, had diagnoses of dementia, a previous infectious gastroenteritis diagnosis, and colitis unspecified. She scored a zero on the SIS assessment, indicating a substantial cognitive impairment. For most of her adult life, “Daisy” gardened and would use the things she grew to help feed her family, as stated by her daughter in passing one day. Her daughter regularly visited her and was supportive of her participating in the sensory garden as indicated by encouraging “Daisy” to come to groups. “Daisy” rarely talked but would contribute to discussions occasionally and would make many facial expressions that corresponded with the conversation.

“Barbara,” a 95-year-old white female, and had a diagnosis of unspecified dementia and delirium. She scored a zero on the SIS assessment, indicating a substantial cognitive impairment. “Barbara” had a hard time hearing and wearing her hearing aids would lead to more agitation, it was observed that she regularly touched them and said they were falling out when they were not. She had a hard time hearing, but would regularly talk at people about church or being a good person. Before living in the memory care unit, she was socially active in her church and the care staff reported that she enjoyed gardening as a hobby. “Barbara” stated she enjoyed growing pretty plants to look at and admire.

“Edith,” a 92-year-old white female, and had diagnoses of mild cognitive impairment, hypertension, vitamin D deficiency, and unspecified atrial defibrillation. She scored a two on the SIS assessment, indicating a significant cognitive impairment. She would often get disoriented and believe it was the incorrect day or year and would state that she was waiting for someone who was supposed to come and would stay in her room instead of interacting with other residents. “Edith” stated multiple times that she wanted to participate more in group activities. “Edith” described helping her mother in the garden and reported that she continued to garden as an adult.

“Cora,” a 95-year-old white female, had diagnoses of Alzheimer’s, familial hypercholesterolemia, muscle weakness, vitamin D deficiency unspecified, and major depressive disorder-recurrent unspecified. She scored a three on the SIS assessment, indicating a significant cognitive impairment. “Cora” regularly talked to people, however, she would get easily frustrated when she was not allowed to do go somewhere.

“Cora” frequently stated that she loved to garden and would talk about the garden she had. She was active in her church and reported that she would use gardening and nature to write poems to relate to God.

Agitation

Agitation was measured using the Agitated Behavior Mapping Instrument (ABMI) and the Cohen-Mansfield Agitation Inventory (CMAI). The ABMI data were collected three times each session and had four subcategories of verbal non-aggressive, physical non-aggressive, verbal aggressive, and physical aggressive behaviors. The CMAI data were collected every two weeks.

ABMI: Verbal Non-Aggressive. Figure 1 displays the average verbal non-aggressive ABMI behaviors for the sample. During baseline A₁, verbal non-aggressive behaviors increased. During intervention B, verbal non-aggressive behaviors initially decreased and continued to decrease but with wide fluctuations between 0.25 and 7.5 verbal non-aggressive behaviors. During intervention BC, there was an initial increase in verbal non-aggressive behaviors followed by a decrease throughout intervention BC with fewer fluctuations than intervention B. During return to baseline A₂, verbal non-aggressive behaviors increased indicating no lasting effects from intervention BC. Overall, intervention BC was more effective than B.

ABMI: Physical Non-Aggressive. Figure 1 displays the average physical non-aggressive ABMI behaviors for the sample. During baseline A₁, physical non-aggressive behaviors decreased and then increased. During intervention B, physical non-aggressive behaviors initially decreased and continued to decrease throughout intervention B.

During intervention BC, the behaviors initially decreased to zero physical non-aggressive behaviors before fluctuating. During return to baseline A₂, they initially increased in physical non-aggressive behaviors before decreasing indicating no lasting effects of intervention BC. Overall intervention BC was more effective at reducing physical non-aggressive behaviors since more sessions had zero physical non-aggressive behaviors and the initial reduction in behaviors between intervention B and BC.

ABMI: Verbal Aggressive. Figure 1 displays the average verbal aggressive ABMI behaviors for the sample. During baseline A₁, verbal aggressive behaviors slightly increased. During intervention B, there was an initial increase in verbal aggressive behaviors that continued to fluctuate between zero and one verbal aggressive behavior. During intervention BC, there was an initial increase in verbal aggressive behaviors followed by a decrease in verbal aggressive behaviors throughout intervention BC. During return to baseline A₂, verbal aggressive behaviors increased indicating no lasting effects from intervention BC. Overall, intervention BC was more effective than intervention B at reducing verbal aggressive behaviors as indicated by more sessions having zero verbal aggressive behaviors.

ABMI: Physical Aggressive. Figure 1 displays the average of physical aggressive ABMI behavior for the sample. During baseline A₁ there was a decrease in physical aggressive behaviors. During intervention B, there was an initial increase in physical aggressive behaviors that decreased throughout intervention B. During intervention BC, there were zero physical aggressive behaviors. During return to baseline A₂, there was a slight increase in physical aggressive behaviors indicating some lasting effect from

intervention BC. Overall, intervention BC was more effective than intervention B at reducing physical aggressive behaviors.

CMAI. Figure 2 displays the CMAI scores for each participant, and Figure 3 displays the average CMAI scores for the sample. During baseline A₁, participants experienced agitation frequently. During intervention B, agitation initially decreased and then increased. During intervention BC, agitation initially decreased and then increased and during return to baseline A₂, agitation decreased. Overall intervention BC was more effective at reducing agitation as indicated by the lower CMAI scores compared with intervention B.

Quality of Life

Quality of life was assessed using the Dementia Quality of Life-Proxy (DEMQOL-Proxy). Data were collected every week and higher scores indicate better quality of life. Figure 3 displays the average DEMQOL-Proxy scores for the sample and figure 4 displays the DEMQOL-Proxy scores for each participant. During baseline A₁, participants' quality of life was stable between 93 and 91.75. During intervention B, quality of life immediately increased and then slightly decreased throughout intervention B. During intervention BC, their quality of life immediately decreased and then increased throughout intervention BC. During return to baseline A₂, quality of life initially increased and was stable between 104.75 and 104.25 indicating high quality of life. Overall, intervention B was more effective at increasing quality of life due to an immediate increase in quality of life in intervention B and more assessment periods during intervention B had higher scores than baseline A₁.

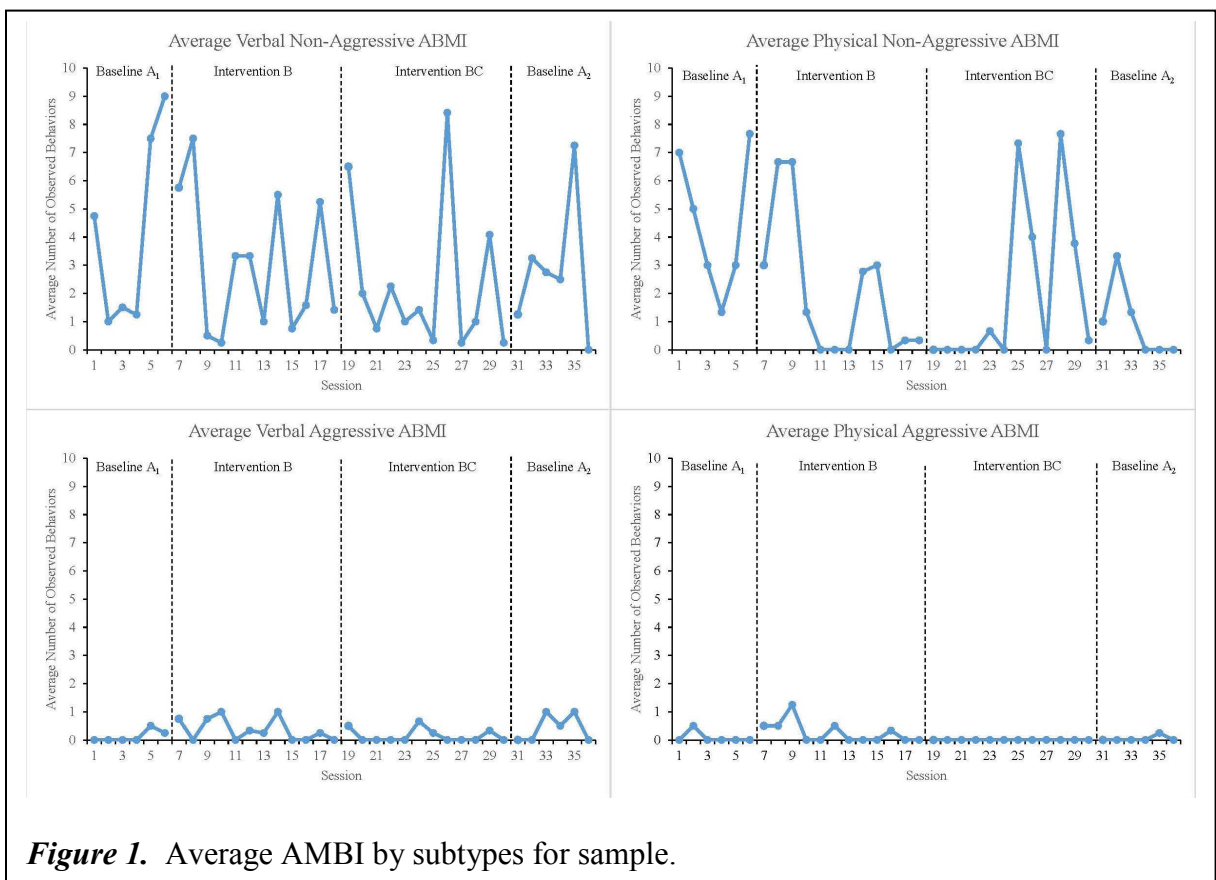
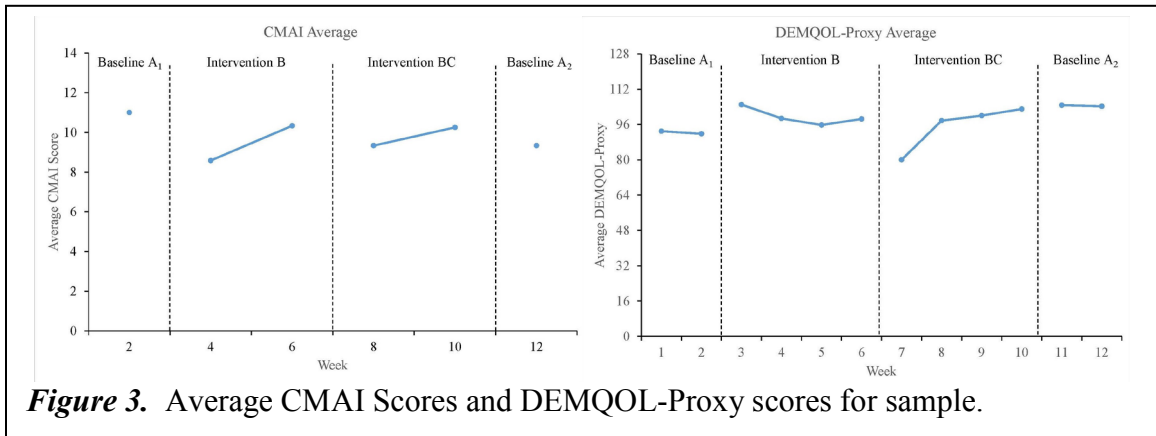
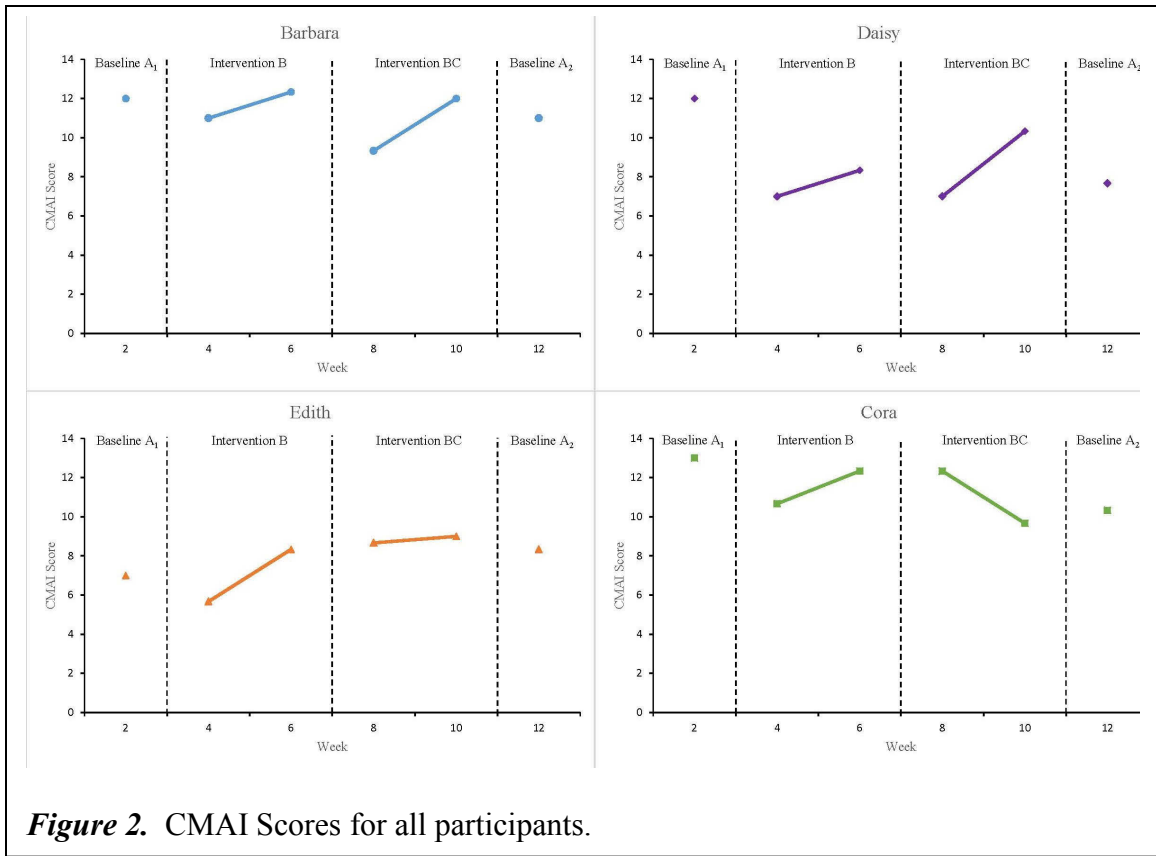
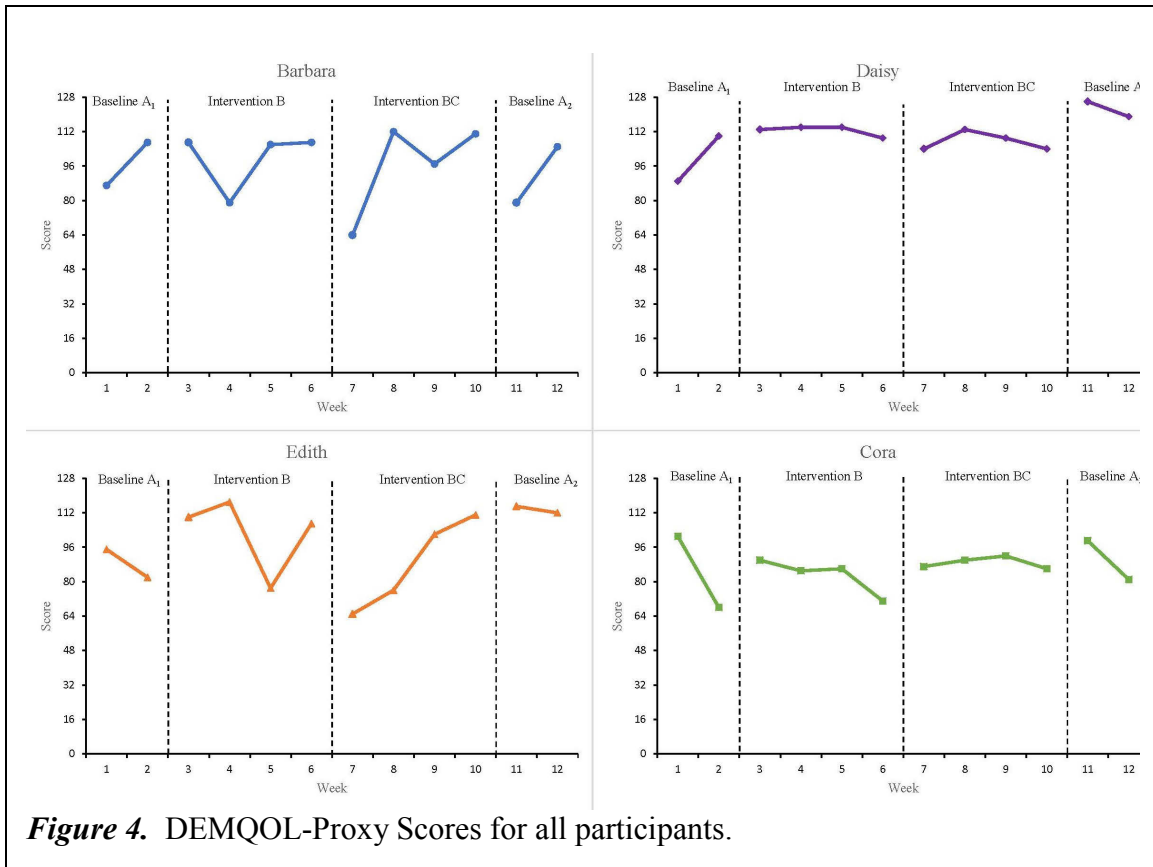


Figure 1. Average AMBI by subtypes for sample.





Discussion

This study found that sensory garden interventions are beneficial for people with dementia by reducing their agitation and improving their quality of life. Participation in the approximated outdoor sensory garden, intervention BC, was shown to reduce agitation more on both agitation measures than the indoor sensory garden, intervention B, based on the average of participants' scores. This result is consistent with previous studies that the environmental difference aids in reducing agitation due to less distraction (Barnicle & Midden, 2003; Rappe & Topo, 2007). The Theory of Supportive Gardens supports this finding as it states that gardens provide a natural distraction that enable individuals in a healthcare setting to have a positive diversion that promotes an improved

emotional state by blocking negative thoughts and worries (Ulrich, 1999). This finding was especially true for “Barbara” and “Cora,” as the approximated outdoor sensory garden, intervention BC, was more effective than the indoor sensory garden, intervention B, at reducing agitation across all sub-types of agitation, verbal non-aggressive, physical non-aggressive, verbal aggressive, and physical aggressive. Contrary to the literature, “Daisy” and “Edith” had a greater reduction in agitation during the indoor sensory garden, intervention B, than in the approximated outdoor sensory garden, intervention BC. However, for “Daisy” this might be explained by her daughter, a daily visitor, being absent during the approximated outdoor sensory garden, intervention BC, and therefore she experienced more agitation due to this change in routine.

Overall, quality of life improved for both intervention B and BC in comparison to baseline A₁. The Model of Psychological Needs & Well-Being in Dementia developed from the Theory of Personhood support this finding as it emphasizes the importance for a person with dementia to be included in meaningful activities that provide comfort, attachment, inclusion, occupation, identity, and agency to maintain or improve their well-being (Kaufman, 2016; Kitwood, 1997). However, quality of life improved and was maintained during intervention B, indoor sensory garden, making it the more effective intervention at improving quality of life. The overall improvements in quality of life from participating in an indoor sensory garden intervention in this study are consistent with previous studies with older adults that used outdoor garden interventions (Edwards, McDonnell, & Merl, 2013; Rappe & Topo, 2007; Thelander, Wahlin, Olofsson, Heikkilä, & Sonde, 2008; Hall et al., 2016; D'Andrea, Batavia, & Sasson, 2007). This finding is

important as it shows improvements in quality of life are more reliant on participating in a sensory garden intervention than the location of the garden.

Quality of life increased throughout intervention BC, however there was an initial reduction following intervention B which may be attributed to the way the approximated outdoor sensory garden was constructed. The sight of a tent constructed in the common area, which was uncommon and out of place, could have been a stressor as it was new to them. If intervention BC were outdoors instead of in an approximated outdoor sensory garden, the results might have reflected the literature (Edwards, McDonnell, & Merl, 2013; Heliker, Chadwick, & O'Connell, 2001; Rappe & Topo, 2007; Thelander, Wahlin, Olofsson, Heikkilä, & Sonde, 2008). “Cora,” on the other hand, was the only participant who did not have an initial reduction in quality of life during intervention BC. This could be due to her not living on the same floor as the interventions, therefore the introduction of a new element into the common area was not a stressor for her as it did not impact her living area. The overall improvement in quality of life supports existing literature that says engaging with nature improves quality of life (Barnicle & Midden, 2003; Edwards, McDonnell, & Merl, 2013; Rappe & Topo, 2007; Hall et al., 2016; D'Andrea, Batavia, & Sasson, 2007).

Limitations

Findings could prove useful to healthcare providers of people with dementia. A constraint on this study was the weather, the temperature was too cold for participants to go outside for an outdoor sensory garden, therefore, an approximation was utilized. Because of this, many factors came into play which affected the results. Noises and

activity from the common area provided distraction at times, and the lack of a natural setting surrounding the participants was not ideal. Further research of these circumstances is needed to determine if there is a significant difference between the effects of an approximated outdoor sensory garden with that of an actual outdoor sensory garden to dementia patients, and if those differences are enough to nullify the effort. The final limitation in this study was the use of an assessment that relied on proxy reporting. Responses varied for the DEMQOL-Proxy assessment based on the individuals who were questioned about each program participant. This limitation was believed to be due to the diverse personal understandings and perspectives of what “quality of life” meant to those questioned, and the interpretations of the participant’s thoughts and feelings.

Implications for Further Research and Practice

Evidence from this study suggests that agitated behaviors decreased most during the approximated outdoor sensory garden, intervention BC, and quality of life improved and maintained better during the indoor sensory garden, intervention B. One area for future research is to determine if there are differences in agitation and quality of life outcomes between an approximated outdoor sensory garden and an outdoor sensory garden. A more thorough understanding of this aspect of the garden may impact facilities that lack the outdoor space but still want to implement a sensory garden. Further research is also needed to improve the ability to generalize these findings through studies with more and diverse participants.

Nevertheless, recreational therapists should consider incorporating sensory gardens into treatment plans for people with dementia who have had a previous or current interest in gardening as it may help reduce agitation and improve quality of life. The basic elements of a sensory garden are non-toxic plants that stimulate the senses and either a spot near a window or under daylight light bulbs. When space is available, the sensory garden can be converted to an approximated outdoor sensory garden, the key pieces being isolated from the typical environment with the use of visual bearers such as curtains with greenery on three sides and open to a window on the fourth. A 1:2 staff to patient ratio when facilitating with people with a significant or substantial cognitive impairment may support active participation and engagement. Overall, a sensory garden may be a useful intervention for any recreation therapy practitioner to use with clients with dementia to decrease agitation and increase quality of life.

Conclusion

The data from this study suggest that sensory gardens are beneficial for people with dementia. These data support the Theory of Personhood, which suggests that participating in a sensory garden helps to fulfill the psychological needs for comfort, attachment, inclusion, identity, agency, and occupation. Participants in this study had a clinically significant reduction in agitated behaviors during the approximated outdoor sensory garden and improvements in quality of life from participating in the indoor sensory garden and the approximated outdoor sensory garden.

CHAPTER 5

Conclusion

The purpose of this study was to determine the impact of sensory garden interventions on people with dementia, specifically their agitation and quality of life. It was a 12-week study designed to look at the difference between an indoor sensory garden intervention and an approximated outdoor sensory garden intervention. A sensory garden intervention was selected because being in a garden for people with dementia has been linked to finding personal meaning, enjoyment, reminiscence, and spiritual healing (Heliker, Chadwick, & O'Connell, 2001). In addition, engaging in nature has been shown to improve quality of life and decrease agitation for people with dementia (Edwards, et al., 2013; Rappe & Topo, 2007). Based on this, it was hypothesized that participating in either an indoor sensory garden or an approximated sensory garden each for four weeks, should decrease agitation and improve quality of life for people with dementia.

After IRB approval, consent was obtained for four participants. Participants were assessed through unobtrusive observations on session days for agitated behaviors, and through proxy assessments every two weeks for overall agitated behaviors and every week for quality of life. Data analysis was based on single-subject design use of clinical significance over statistical significance, allowing the researcher to determine the effect an intervention has on specific behaviors for subjects of interest (Dattilo, et al., 2000; Tawney & Gast, 1984). This multiple treatment single subject study found that people with dementia had improvements in quality of life and decreased agitated behaviors when participating in a sensory garden intervention for eight weeks. Averaged for all

participants, agitated behaviors decreased most during the approximated outdoor sensory garden, intervention BC, and quality of life improved and maintained better during the indoor sensory garden, intervention B.

Contributions and Practical Applications

The results of this study build upon those of Hall et al. (2013) and demonstrate that the therapeutic use of a sensory garden helps to increase quality of life and decrease agitation. This study contributes to the growing body of knowledge about how to treat people with dementia. It adds to the field of RT's understanding of sensory stimulation and the use of nature-based interventions (Bedini, 2009; Buettner & Fitzsimmons, 2003; McCormick & Lee, 2001; Stumbo, 2003;). A sensory garden should be considered as an intervention as it has been shown to be personally meaningful to garden for people with dementia (Gibson, et al., 2007; Heliker, Chadwick, & O'Connell, 2001) and the results of this study showed a decrease in agitation and improvements in quality of life for both an indoor sensory garden and an approximated outdoor sensory garden intervention.

Based on the participants in this study, an indoor sensory garden can be used to improve quality of life for those with dementia living in a long-term care facility. An indoor sensory garden can easily be constructed in any long-term care facility. The basic elements are non-toxic plants that stimulate the senses and either a spot near a window or under daylight light bulbs. When space is available, the sensory garden can be converted to an approximated outdoor sensory garden, the key pieces being isolated from the typical environment and near a window. This sensory garden intervention can then aid in reducing agitated behaviors year-round based on the participants of this study. Another

factor to consider is keep the sensory garden group small. Having a 1:2 staff to patient ratio when facilitating with people with a significant or substantial cognitive impairment may support active participation and engagement. Overall, a sensory garden may be a useful intervention for any RT practitioner to use with clients with dementia to decrease agitation and increase quality of life.

Limitations

There were some limitations that occurred in this study. First, the weather affected the way intervention BC was constructed. The original plan was to have an outdoor sensory garden. The study started later in the fall than anticipated due to obtaining consent taking longer than expected. By the time intervention BC was set to start, the temperature dropped below 50°F for all intervention days. Due to the low temperatures, the approximated outdoor sensory garden was created. To limit the impact of using an approximated outdoor sensory garden instead of an outdoor sensory garden, the garden was set up against a full-length window directly under a light. The walls of the tent used to separate the sensory garden from the common area were green with leaf patterns on it to have a more natural atmosphere than a view of the common area. While these modifications helped to mitigate the impact of using an approximated sensory garden, it is unsure exactly how and if results were affected.

Lastly, the quality of life assessment used, DEMQOL-Proxy, required that caregivers be interviewed about their interpretation of the participants quality of life. Based on who was interviewed, the reports varied; this was believed to be due to the

diverse personal understandings and perspectives of what “quality of life” meant to those questioned, and the interpretations of the participant’s thoughts and feelings

Summary

Despite the limitations previously discussed, the results of this study provide useful information to people working with individuals with dementia. Recreational therapists can implement sensory gardens with their clients knowing that it might improve their quality of life and help manage their agitated behaviors. Researchers have gained an understanding of the use of sensory gardens for those with dementia and can now further explore the use of other nature-based interventions or sensory stimulation interventions to serve those with dementia. Results from this study indicate the need for the continued research of innovative recreation therapy interventions to improve life for those with dementia.

APPENDICES

Appendix A
Six Item Screener

Six Item Screener (SIS)

Instructions: Special missing values are allowed for cases where the response "Don't know", "Refused", "Unknown", or "N/A" is not listed as an option.

Examiner: _____ Date: _____ Code: _____

INTRODUCTION SCRIPT: "Next, I will ask you a few questions that ask you to use your memory and attention. I am going to say three words. After I've said all three words, I would like you to say them back to me. Try to remember what the words are, because I am going to ask you to name them again in a few minutes. Please do not write the words down. Ready?"

"Please repeat these words for me: APPLE - PENNY - TABLE." (Interviewer may repeat words 3 times, if necessary)

If the participant begins to say each word immediately after it has been read, say: "Let's try it again. This time wait until I have said all three words, and then say them back to me."

After a failed attempt, say: "Let's try it again."

1. Was the task attempted?

☐ Yes →

GO TO QUESTION 2

☐ No

1a. If no, reason: ☐

H = Hearing loss

P = Participant

unable to

comprehend

instructions

(cognitive

impairment)

R = Refusal

O = Other 1a1. _____

END ASSESMENT

2. Were the words repeated correctly? ☐ Yes

☐ No →

**ANSWER QUESTIONS 3, 4, and 5.
Skip 6, 7, and 8.**

	Correct	Incorrect	Not Attempted/ Refusal
3. Thank you, now, without looking at a calendar or watch: What year is this?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Without looking at a calendar or watch: What month is this?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Without looking at a calendar or watch: What is the day of the week?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If participant gives the date, say: "Good, and what day of the week is it?"

"Now, what were those three words I asked you to remember?"

	Correct	Incorrect	Not Attempted/ Refusal
6. APPLE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. TABLE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. PENNY	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

NOTE: A response of "I don't know" is scored as 'Incorrect'. A self-corrected response is scored as 'Correct'.

Appendix B
Agitation Behavior Mapping Instrument

AGITATION BEHAVIOR MAPPING INSTRUMENT					
BEHAVIOR (E=Extreme C=constant, ✓=discrete)	DIRECTION & SOCIAL ENVIRONMENT		I=Individual S, O, G=Group C, U	(D-Different Unit S-Same Unit)	
	SELF		ACTIVITY & INITIATION	LOCATION	
Request for attention, help; asking questions; repeat words, sentences	NUMBER OF STAFF		Sleep	own room	
	Male, Female, Both		Dozing or Borderline sleep	other patient's room	
	Black, White, Hispanic, Other, Both		get up/go to sleep	on bed	
constant talk	new (Yes, No, Both)		grooming, dressing	on floor	
make strange noises	Professional, Assistant,		bathing, toileting	shower	
babble	Housekeeping, Observer, Both		chair ambulation	toilet own	
screams	active triggering (Verbal, Touch, Other, No, V+T)		play, dance	toilet other	
cry, weep, inappropriate laughter			eating	dining room	
walk aimlessly (including in wheelchair), pace, constant search	NUMBER OF RESIDENTS		write, read (look at book or magazine)	corridor	
	Male, Female, Both		TV, radio, music	activity/day room	
	Same unit, Different unit, Both		social-private	nurses station	
strange movements, make faces, walk, stand, or sit when inapprop.	new to the unit (Yes, No, Both)		visiting	In, Around, Both	
hide things, repetitious mannerism	cognitive functioning (L,M,H,B)		talk to/or to the phone/to nothing	elevators	
robe inappropriately	physical functioning (L,M,H,B)		structured activity	other	
disrobe inappropriately or expose self	active triggering (Verbal, Touch, Other, No, V+T)		traffic		
peep, look at someone obtrusively	NUMBER OF OTHERS		None,	ENVIRONMENT	
try to get to a different place (try to open a door, get into the elevator, ask to get out)	Male, Female, Both		Treatment	TV	
	Child, Spouse, Sibling, Other		Bed-ambulation	music	
	Family, Friend, Volunteer, Other			noise N,L,M,H,U	
moving towards someone (Touch, Near-less than 1 ft.) rub against	Resident's Family, Other			distance from nearest person	
	estimated age			Touch,	
total rigidity	active triggering (V,T,O,N,V+T)			O (1ft. or less)	
make noise through banging, etc.	INANIMATE OBJECT			N (1-3 ft.)	
negative, complain, accuse (verbal)	NOTHING		BODY POSITION	F (more than 3 ft.)	
curse, verbal aggression	REACTION (Pleasant, Corrective, Obey, None, Unpleasant, Other Indifferent, Corrective-Pleasant)		Lie down	restraints	
sexual advances and behavior			sitting	temperature C,N,H	
Vocal, Physical			standing	light B,N,D	
try to get out of restraints	staff		Naked, Inappropriate dress, partially dressed	Wet or Soiled	
refuse, uncooperative (non-verbal)	resident		falling	Out of sequence, Not found, Unobservable	
situate self or other in hazardous place; hurt self or other with substance; intentional falling; eat, drink, inappropriate things	other		Contorted position Leaning, Diagonal possible incident report		
	SLEEP PATTERN				
hit, fight, kick, try to hit	eyes - O,C,F,U,B				
grab onto, push, pull people	snoring				
bite, scratch	loudness of breathing L,M,H,U,I			Unit	
spit inappropriately	rate of breathing S,M,F,U,I			Shift D E N	
throw things; handle, pick things, grab onto things, move things	discontinuity of sleep			Month/Day /	
tear things; destroy property	discontinuity of breathing			Weekday	
other inappropriate behavior	body restlessness/turning			Time	
	myoclonic movement			Observer	

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Appendix C
Cohen-Mansfield Agitation Inventory

THE COHEN-MANSFIELD AGITATION INVENTORY - short form

Please read each of the agitated behaviors, and check how often (from 1-5) they were manifested by the participant over the last 2 weeks; if more than one occurred within a group, add the occurrences, e.g., if hitting occurred on 3 days a week, and kicking occurred on 4 days a week, $3 + 4 = 7$ days; circle 4, once or several times a day.

	Never 1	Less than once a week 2	Once or several times a week 3	Once or several times a day 4	A few times an hour or continuous for half an hour or more 5
1. Cursing or verbal aggression	1	2	3	4	5
2. Hitting (including self), Kicking, Pushing, Biting, Scratching, Aggressive Spitting (include at meals)	1	2	3	4	5
3. Grabbing onto people, Throwing things, Tearing things or destroying property	1	2	3	4	5
4. Other aggressive behaviors or self abuse including: Intentional falling, Making verbal or physical sexual advances, Eating/drinking/ chewing inappropriate substances, Hurt self or other	1	2	3	4	5
5. Pace, aimless wandering, Trying to get to a different place (e.g., out of the room, building)	1	2	3	4	5
6. General restlessness, Performing repetitious mannerisms, tapping, strange movements	1	2	3	4	5
7. Inappropriate dress or disrobing	1	2	3	4	5
8. Handling things inappropriately	1	2	3	4	5
9. Constant request for attention or help	1	2	3	4	5

	Never 1	Less than once a week 2	Once or several times a week 3	Once or several times a day 4	A few times an hour or continuous for half an hour or more 5
10. Repetitive sentences, calls, questions or words	1	2	3	4	5
11. Complaining, Negativism, Refusal to follow directions	1	2	3	4	5
12. Strange noises, (weird laughter or crying)	1	2	3	4	5
13. Hiding things, Hoarding things	1	2	3	4	5
14. Screaming	1	2	3	4	5

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Appendix D
Dementia Quality of Life-Proxy

DEMQOL - Carer (version 4)

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about _____ (your relative's) life, as you are the person who knows him/her best. There are no right or wrong answers. Just give the answer that best describes how _____ (your relative) has felt in the last week. If possible try and give the answer that you think _____ (your relative) would give. Don't worry if some questions appear not to apply to _____ (your relative). We have to ask the same questions of everybody.

Before we start we'll do a practise question; that's one that doesn't count. (Show the response card and ask respondent to say or point to the answer). In the last week how much has _____ (your relative) enjoyed watching television?

a lot quite a bit a little not at all

Follow up with a prompt question: Why is that? or Tell me a bit more about that.

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For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask you about _____ (your relative's) feelings. In the last week, would you say that _____ (your relative) has felt _____.

- | | | | | |
|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 1. cheerful? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 2. worried or anxious? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 3. frustrated? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 4. full of energy? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 5. sad? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 6. content? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 7. distressed? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 8. lively? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 9. irritable? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 10. fed-up | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 11. that he/she has things to look forward to? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

Next, I'm going to ask you about _____ (your relative's) memory. In the last week, how worried would you say _____ (your relative) has been about _____.

- | | | | | |
|--|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 12. his/her memory in general? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 13. forgetting things that happened a long time ago? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 14. forgetting things that happened recently? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 15. forgetting people's names? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 16. forgetting where he/she is? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 17. forgetting what day it is? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

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- | | | | | |
|-------------------------------------|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 18. his/her thoughts being muddled? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 19. difficulty making decisions? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 20. making him/herself understood? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

Now, I'm going to ask about _____ (your relative's) everyday life. In the last week, how worried would you say _____ (your relative) has been about _____.

- | | | | | |
|--|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 21. keeping him/herself clean
(eg washing and bathing)? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 22. keeping him/herself looking nice? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 23. getting what he/she wants
from the shops? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 24. using money to pay for things? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 25. looking after his/her finances? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 26. things taking longer than
they used to? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 27. getting in touch with people? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 28. not having enough company? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 29. not being able to help other
people? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 30. not playing a useful part
in things? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 31. his/her physical health? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

We've already talked about lots of things: _____ (your relative's) feelings, memory and everyday life. Thinking about all of these things in the last week, how would you say _____ (your relative) would rate ..

32. his/her quality of life overall? ** ☐ very good ☐ good ☐ fair ☐ poor

** items that need to be reversed before scoring

Appendix E

Dementia Quality of Life

DEMQOL (version 4)

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about your life. There are no right or wrong answers. Just give the answer that best describes how you have felt in the last week. Don't worry if some questions appear not to apply to you. We have to ask the same questions of everybody.

Before we start we'll do a practise question; that's one that doesn't count. (Show the response card and ask respondent to say or point to the answer) In the last week, how much have you enjoyed watching television?

a lot quite a bit a little not at all

Follow up with a prompt question: Why is that? or Tell me a bit more about that.

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For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask about your feelings. In the last week, have you felt.....

- | | | | | |
|--|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 1. cheerful? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 2. worried or anxious? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 3. that you are enjoying life? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 4. frustrated? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 5. confident? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 6. full of energy? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 7. sad? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 8. lonely? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 9. distressed? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 10. lively? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 11. irritable? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 12. fed-up? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 13. that there are things that you wanted to do but couldn't? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

Next, I'm going to ask you about your memory. In the last week, how worried have you been about.....

- | | | | | |
|--|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 14. forgetting things that happened recently? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 15. forgetting who people are? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 16. forgetting what day it is? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

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- | | | | | |
|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 17. your thoughts being muddled? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 18. difficulty making decisions? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 19. poor concentration? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

Now, I'm going to ask you about your everyday life. In the last week, how worried have you been about.....

- | | | | | |
|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 20. not having enough company? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 21. how you get on with people close to you? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 22. getting the affection that you want? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 23. people not listening to you? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 24. making yourself understood? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 25. getting help when you need it? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 26. getting to the toilet in time? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 27. how you feel in yourself? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 28. your health overall? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

We've already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate.....

- | | | | | |
|---|------------------------------------|-------------------------------|-------------------------------|-------------------------------|
| 29. your quality of life overall? ** | <input type="checkbox"/> very good | <input type="checkbox"/> good | <input type="checkbox"/> fair | <input type="checkbox"/> poor |
|---|------------------------------------|-------------------------------|-------------------------------|-------------------------------|

** items that need to be reversed before scoring

Appendix F
Informed Consent Form



CONSENT TO PARTICIPATE IN A RESEARCH STUDY

The Impact of Recreational Therapy Outdoors for People with Dementia Utilizing Sensory Gardens

Study to be Conducted at: Creekside Cottage
Clemson Downs
500 Downs Loop
Clemson, SC 29631

Principal Investigator: Marieke Van Puymbroeck, Ph.D., CTRS, FDRT (864) 656-1189

Co-Investigator: Haley Collins, BS (803) 522-0248

For powers of attorney or legal guardians of Creekside Cottage residents, please note that any words referring to “you” (such as I, me, myself, you, your, yourself) also refer to “the resident” throughout this consent form. Permission from you is required for the resident to participate in this study.

This Informed Consent Form has two parts:

- **Information Sheet (to share information about the research with you)**
- **Certificate of Consent (for signatures if you agree to take part)**

You will be given a copy of the full Informed Consent Form

PART I: Information Sheet

Introduction

I am a graduate student at Clemson University working on my Master’s thesis. I am conducting a research on the effect of recreational therapy outdoors on reducing agitation and improving well-being for people with dementia. I would like to invite you to participate in this study, below you will find more information and you can take your time to decide to participate or not. If you have questions feel free to contact me.

Purpose of the Study

You are being asked to participate because you have been identified by staff as a resident of Creekside Cottage having at least one disruptive behaviours and/or a period of agitation with the past two weeks. The purpose of this study is to learn if recreational therapy outdoors can reduce agitation and improve well-being for people with dementia more so than recreational therapy indoors. Information obtained in this study may be valuable in developing future care plans for people with dementia.

Eligibility Criteria

You must meet the following criteria to participate in this study:

- Diagnosis of dementia
- Have an identified current or previous interest in gardening
- Stable on current medications

- Have been identified by staff as having at least one disruptive behavior and/or a period of agitation with the past two weeks
- You will be excluded from the study if there is a known reason you would be unable to participate in sessions three times a week for 30-45 minutes

Procedures

You will be asked to participate in a sensory garden intervention at Creekside Cottage three times a week for 30-45 minutes for eight weeks, four weeks outdoors and the other four weeks indoors. A sensory garden is a garden that stimulates all the senses. You will be prompted to use all your senses and discuss your feelings about your senses and memories they recall in a group with the researcher and one other participant. During this study there will be a variety of assessments, the assessments are:

- Agitated Behavior Mapping Instrument (ABMI)
 - This is a series of observations prior, during, and after intervention sessions on your expressed agitation made by me or a research assistant from a distance.
- Cohen-Mansfield Agitation Inventory (CMAI)
 - A research assistant or me will interview your primary caregiver on your agitation over the previous two weeks and will be done every two weeks of the study starting on the first day.
- Dementia Quality of Life (DEMQOL) or Dementia Quality of Life-Proxy (DEMQOL-Proxy)
 - Either you or your caregiver will be interviewed by a research assistant or me at the end of every week to determine your current quality of life and will take 10-15 minute to complete.
- Mini Mental Status Examination

This will be used to determine if the DEMQOL or DEMQOL-Proxy is appropriate to use for you. It measures your cognition level and the nurse manager at Creekside Cottage will be administering this the first week of the study, it only takes 5-10 minutes.

In addition, basic demographic information such as age, gender, race, and diagnosis will be obtained from Clemson Down's records or you.

Benefits

There is no guarantee that you will receive any benefits from participation. You may experience a decrease in agitation and improved well-being. In addition, all Recreational Therapy sessions will be provided at no charge to you.

Risks

Any therapy has possible side effects. The therapies and procedures used in this study may cause all, some, or none of the side effects listed. There is always the risk of very uncommon or previously unknown side effects happening.

- There are no known risks for participation in this study. The only risks could be
- anxiety related to participating in a new activity.
- There are no known side effects related to participation in this study.

Cost to You

There will be no cost to you for participating in this study. The costs of any procedures used in this study will be paid for by the investigator. The investigator will not pay for your usual medical care.

Payment

You will not be paid to participate in this study.

Voluntary Participation

Participation in this study is completely voluntary. You may refuse to participate or withdraw from the study at any time. If you do not want to sign this form, you cannot be in this study. If you refuse to participate or withdraw from the study, you will not be penalized or lose any benefits. Your decision will not affect your relationship with your doctor or nursing home.

Confidentiality

All information collected will be kept on a password-protected computer and a code number will be used instead of your name.

Contact Information

Please take as much time as you need to think about if you want to be in the study. If you have any questions about this study at any time, contact the research team:

Haley Collins, BS (803) 522-0248, hecolli@g.clemson.edu

This proposal will be reviewed by Clemson IRB, which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about the IRB, contact irb@clemson.edu.

PART II: Certificate of Consent**Agreement to Participate in This Study and Permission to Use and Disclose My Health Information**

I have read the information presented in this informed consent form. I have had an opportunity to ask questions and all my questions have been answered to my satisfaction. This form is being signed voluntarily by me, indicating my agreement to participate in this study, until I might decide to withdraw my consent. I will receive a copy of this signed consent form. I understand that by signing this consent form I do not give up any of my legal rights by agreeing to participate.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research.

Printed Name of Participant or Guardian

Signature of Participant or Guardian

Date

Time

Signature of Witness

Date

Time

Signature of Witness to Participant's Verbal Assent

Date

Time

REFERENCES

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